Program of All-Inclusive Care for the Elderly (PACE) Quality

Member Outcomes:

The Initial Assessment

June 2002

Department of Health and Family Services
Office of Strategic Finance
Center for Delivery Systems Development

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Executive Summary

The Department of Health and Family Services is using several methods, both traditional and innovative, to measure and assure quality in the Program of All-Inclusive Care for the Elderly (PACE). The PACE Program is operated in Milwaukee by a not-for-profit organization, Community Care for the Elderly (CCE). The PACE Program integrates acute and chronic health and long-term support services, home and community-based services, physician services, and all medical care for elderly individuals. Traditional methods of quality assurance include procedures such as monitoring a contractor's compliance with contract requirements and reviewing logs of complaints and grievances.

The quality and effectiveness of PACE services are also being assessed with an innovative method based upon 14 "member outcomes," which will enable the Department and the contractor to ensure that the long-term care services are in fact producing results that are desired by each member. These outcomes were identified by a group of members, providers, advocates, and staff of the Department's Center for Delivery Systems Development, Bureau of Developmental Disabilities Services (BDDS), Bureau on Aging and Long-Term Care Services (BALTCR), and the Centers for Medicare and Medicaid Services.

PACE Member Personal Outcomes

Self-determination and choice outcomes

1. People are treated fairly.
2. People have privacy.
3. People have personal dignity and respect.
4. People choose their services.
5. People choose their daily routine.
6. People achieve their employment objectives.
7. People are satisfied with services.

Community Integration outcomes

8. People choose where and with whom they live.
9. People participate in the life of the community.
10. People remain connected to informal support networks.

Health and Safety outcomes

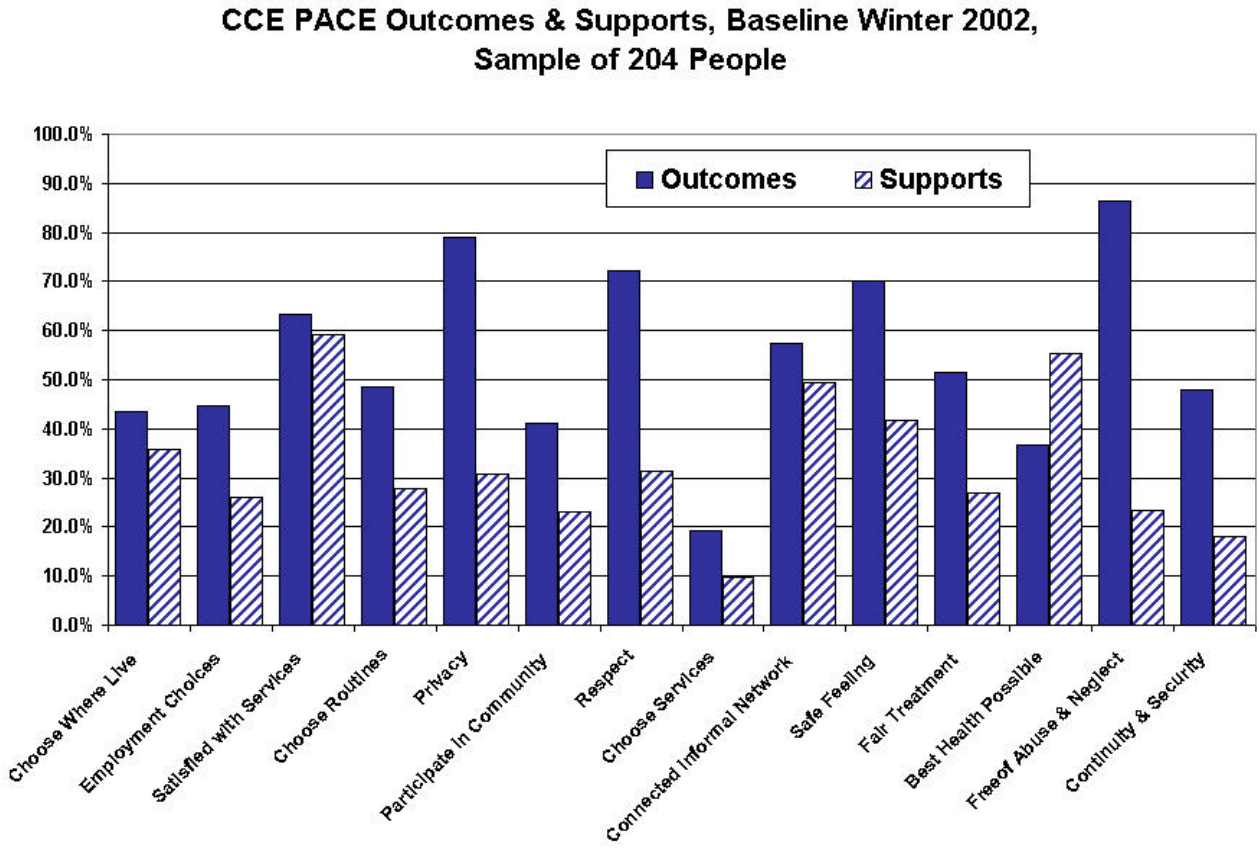
11. People are free from abuse and neglect.
12. People have the best possible health.
13. People are safe.
14. People experience continuity and security.

Because individuals have personal preferences, different services are needed to achieve the same outcome for different people. For example, satisfaction of the outcome "People have a choice about where and with whom they live" would require different services for an individual who prefers living alone and an

individual who prefers a congregate setting, although each might be residing in housing that appears safe and appropriate to others.

This report contains the results of the first series of member outcome interviews with 204 randomly selected PACE members and their lead team member. In conversations with these members conducted during an eleven-week period from November 2001 through February 2002, trained interviewers determined whether each outcome was present in each member's life. The members' lead care managers were also interviewed to determine whether the contractor had identified the member's preferences for each outcome and was providing the member with services or supports to assist the member in achieving the outcome. The sample size is statistically significant at a 95% level of confidence and 5% confidence interval.

The interviewers were trained in outcome assessment techniques developed by the Council on Quality and Leadership (the Council), a nationally recognized authority for the accreditation of long-term care programs for people with disabilities. These techniques, which the Council has been refining for more than ten years for use with people with disabilities, were adapted for use in Wisconsin in consultation with the Council. In particular, BALTCR staff was helpful in refining the interview questions and techniques for use with elderly individuals. For example, the outcome, "People achieve their employment objectives" was framed for elderly individuals to assess whether they were involved in daytime activities that they considered meaningful and fulfilling.



The results presented here show, for each of the 14 outcomes, the proportion of interviewed members for whom their desired outcomes were present (outcomes present) and the proportion of interviewed members for whom the contractor was found to be providing supports tailored to achieve those outcomes (supports provided.)

The Department has not yet identified benchmarks or targets for each outcome. No one can expect complete attainment of all outcomes—it is unrealistic to expect that all desired outcomes will be present at any given time for any individual, either with or without a need for long-term care. People can and do maintain some hopes and dreams that may be difficult or even impossible to achieve. The Department expects, however, that it will be possible to identify performance benchmarks after additional data from PACE and other programs are accumulated to provide a basis for comparison.

The value of the data obtained in the first round of outcome interviews of PACE members lies in the guidance it provides to quality improvement efforts. Staff noted early in the interview process that they had limited knowledge of the member's home situation and thus were not providing much support for some of the outcomes. To better serve members, staff developed a tool to be used three times each year to assess the home environment and incorporate the findings into the care plan. Nursing and social work staff will be the primary disciplines making the home visits; however, occupational and physical therapy staff are available when the screening tool indicates the need.

Department and contractor staff are analyzing and interpreting the results, which will be used to identify directions for quality improvement efforts at both the state and local levels. For example, the outcome "People choose their services" will receive attention from the Department and contractor. Despite the emphasis that the design of the PACE program has placed on responsiveness to individuals' needs and desires, only 19.1% of the interviewed members indicated that they choose their services. Although just 19.1% of interviewed members chose their services, 63.2% were satisfied with their services. When the PACE program first started, members were required to participate in the day program. That requirement no longer exists. However, some people may have entered the program while that requirement existed and their response may have been affected by that requirement. When people enroll in PACE, they usually switch from their primary physician to the PACE program's physician but usually retain their specialists and hospital affiliation.

Supports for outcomes ranged from 9.8% to 59.3% of the interviewed members. Outcomes met ranged from 19.1% to 86.3% of the interviewed members. The three times per year home assessment is expected to increase supports provided. Department and contractor staff are considering what other factors may have contributed to the disparity between outcomes met and supports provided.

Staff will also focus on aggregate outcomes that were present for more members. For example, the outcome of "People are free from abuse and neglect" was present for more members (86.3%) than any other outcome, even though the level of support provided by the contractor was relatively low (23.5%). The Department is working on more detailed analyses of these data to determine whether certain outcomes correlate with certain living situations.

The information from the member outcomes will provide important context for other quality assurance efforts, such as the review of individual service plans. The Department has begun training all care management staff in the PACE member outcomes, and a second series of outcome assessments, with a separately selected sample of members, will occur in the future.

In addition, the contractor will receive and be able to use the outcome assessments of its members to evaluate its own performance. Local long-term care groups will also have access to summary data—without personal identifiers to preserve confidentiality—about the outcomes of people enrolled in PACE.

The Department also plans to continue to assess member outcomes in other programs, such as the Wisconsin Family Care and Partnership Programs. The information gathered from the member outcome assessments in PACE and other programs will help discern organizational, service, or support characteristics that are associated with the best possible outcomes.

More importantly, we hope that focusing on member outcomes will promote consistent attention at all levels to our ultimate purpose: improving the quality of life for people who need the services. CCE staff quickly initiated a three times per year home visit process to increase their knowledge of the member's home environment and what the member's goals were.

At the local level, outcomes-focused care managers and providers will listen to the individuals who receive the services and find flexible, creative ways to provide support for their desired outcomes. At the Department level, outcome-focused staff will find ways to identify and share best practices among local programs to assist them in meeting equally high levels of performance. Outcome-focused state and federal policy makers will be able to direct resources to the most cost-effective programs.

Introduction

The Program of All-Inclusive Care for the Elderly (PACE) is a comprehensive program of services for older adults in Wisconsin and in 13 other states at 25 different locations. The program integrates health and long-term support services, and includes home and community-based services, physician services, and all medical care. A more detailed description of the PACE Program is included as Appendix I.

Member choice is a cornerstone of the PACE Program. Program agencies make every effort to honor member preferences of how, when, and where services are delivered.

A key component of the PACE Program is team-based care management. Under this arrangement, the participant, his or her physician, and a team of nurses and social workers develop a care plan together. The team coordinates all service delivery.

To participate in the PACE Program, people must be eligible for Medicaid and be certified at the Medicaid nursing home level of care. The program also serves people who are eligible for both Medicaid and Medicare. Participation in the program is voluntary.

PACE Goals

The goals of PACE are to:

- Improve quality of health care and service delivery while containing costs;
- Reduce fragmentation and inefficiency in the existing health care delivery system, and
- Increase the ability of people to live in the community and participate in decisions regarding their own health care.

The PACE Program began operations in Wisconsin in 1990 at CCE (Community Care for the Elderly) and now operates as a fully-capitated, dual Medicaid and Medicare program. Under this arrangement, CCE entered into a Medicaid managed care contract with the Wisconsin Department of Health and Family Services and a Medicare contract with the federal Centers for Medicare and Medicaid Services. CCE receives monthly capitation payments for each member. From these funds, CCE pays for all member services and is responsible for the member's care regardless of where or which agency provides the services.

As of January 1, 2002, about 450 people were enrolled in PACE at the Community Care for the Elderly program in Milwaukee, Wisconsin, a community-based, not-for-profit contractor.

CCE PACE operates extensive internal quality assurance and improvement programs and reports regularly on carefully defined data elements that provide information on indicators of quality care.

Outcomes Focus on Members' Quality of Life Rather Than Processes

Traditionally, expectations for quality in human services have been expressed in terms of the service providers' compliance with prescribed standards, such as the frequency of contact with the member, hours of personal care, and the professional qualifications of service providers. While the Department has consistently sought to purchase only quality services, we need to address a critical question: if a connection between a program's services and individual outcomes desired by the member cannot be demonstrated, is it cost-effective to purchase that service or to fund that program?

The Department's Center for Delivery Systems Development convened the "Designing Quality Work Group" in December 1997. This work group included members, providers, advocates, and staff of the department's Bureau of Developmental Disability Services (BDDS), Bureau on Aging and Long-Term Care Resources (BALTCR), and the Centers for Medicare and Medicaid Services. The group established three core elements of a member-centered approach to quality assurance. First, the system was to be based upon outcomes relating to the members' health and quality of life rather than on the attributes of the services. Second, the quality assurance system was to incorporate objective assessment of whether these outcomes were present for each individual enrolled in PACE; and finally, it was to provide for system improvement based on these objective assessments.

The work group refined a list of 14 outcomes, shown on the following page. These outcomes are:

- Global, applying to all people, seniors and non-seniors, people with or without disabilities, and people who are ill or well;
- Holistic, covering the quality-of-life aspects of community integration, self-determination, and choice, as well as health and safety; and
- Designed to take into account each individual's attitudes, beliefs, culture, behaviors and environmental circumstances.

Each person defines the circumstances that achieve the outcome for his or her own life. For example, one person might want to live alone, while another might prefer to live in a congregate setting. Different services are needed to achieve the same outcome—having a choice about where and with whom to live—for both. This approach to quality is based on a belief that members, not providers, should determine what results they want and need from services and supports.

PACE Member Personal Outcomes

Self-determination and choice outcomes

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The link between outcomes and services, is made by asking two separate questions:

- Is each outcome present for each person as he or she defines it?
- Is the contractor providing supports and services to promote achievement of those outcomes?

All desired outcomes cannot be expected to be present at any given time, either for people with or people without disabilities. However, the professionals in a consumer-centered system need to listen to and learn from each person, identify the values and preferences that define his or her desired outcomes, and incorporate these into the individual's service plans.

For example, if a person who lives in a congregate setting prefers to live alone, the outcome "choose where and with whom to live" is not present. However, if the individual's care plan includes both services to help the individual learn the skills necessary to live alone and a process to develop an independent living situation, the supports are being provided to help achieve the outcome.

If the person who lives in the congregate setting is aware of available choices and truly does prefer to live there, the outcome, "choose where and with whom to live" is present. However, the person's care manager may never have talked to the person about his or her options or desires for a living situation. In that case, supports for the outcome are not being provided.

Member Outcomes Are Objectively Assessed

To develop these assessment methods, the Department drew upon methodology developed by the Council on Quality and Leadership (the Council), a nationally recognized authority for the accreditation of long-term care programs for people with disabilities. For more than ten years, the Council has been refining interview and information-collection methods that enable trained interviewers to determine whether member outcomes are present and whether outcome-based supports are provided. These methods incorporate interviewing techniques that vary depending upon the verbal skills of the members. Interviewers use decision-making guidelines to determine a person's personal preferences for social and support networks, lifestyles and role functions, activities, and other factors related to outcomes, and whether those outcomes are present in the person's life. The process also incorporates methods for ensuring that all interviewers are using the process the same way ("inter-rater reliability.")

Although the Council's experience has been mostly with people with disabilities, rather than with elderly people, the Department has been working with the Council to adapt the assessment techniques to the needs of elderly members. In particular, BALTCR staff has been, and continues to be, helpful in refining the interview questions and techniques for use with elderly individuals. For example, the outcome, "People achieve their employment objectives" was framed for elderly individuals to assess whether they had meaningful and fulfilling daytime activities. The Department assessed the presence of the outcomes by gathering information directly from a randomly selected sample of PACE members in face-to-face conversations. Interviewers also contacted the lead professional of each member's care management team. Using decision-making guidelines similar to those used for the member interviews, the interviewer determined whether outcome-based support was being provided to the member. If the care manager was familiar with the person's needs and preferences and had taken steps to promote the achievement of the outcomes as desired by that individual, the interviewer determined that support had been provided to achieve member-defined outcomes.

Assessment of Outcomes and Supports Provides a Basis for System Improvement

Traditional methods of monitoring quality focus on compliance with standard procedures and organizational processes, and emphasize documentation of compliance with regulations. These traditional systems typically depend upon the judgment of professional inspectors. The result is the identification of deficiencies requiring plans of correction, and administrative sanctions that may involve threats of loss of funds or fines.

In contrast, focus on assessing member outcomes will better enable providers to know and understand their clients as people with goals similar to their own and will provide an incentive to adapt services more creatively to the needs of each unique individual. No longer will it be acceptable to provide services that do no more than meet minimum licensure standards; providers will be expected to support the

achievement of desired results for the individuals. Knowledge about outcomes enables members and their families to reject services that are ineffective, and allows policy makers to redirect resources to programs that do a better job of improving the health and well being of their members.

CCE PACE is required to have an internal quality assessment and improvement program that collects and reports information on desired member outcome measures and identifies people who do not achieve desired outcomes. This quality assessment and improvement program allows staff to continuously monitor and evaluate its own performance and that of its providers.

At the state level, CCE PACE outcomes will be measured periodically by selecting a sample of members, interviewing them and their lead care managers, and analyzing the compiled results. The first series of these assessments, which established the initial measures of outcomes and supports, was carried out between November 2001 and February 2002. This report presents the first results of those assessments. More detailed analyses may be conducted by the Department and the contractor to observe possible relationships between the presence of outcomes or supports and factors such as the nature of the person's disability or where he or she lives.

The results are not to be considered a numeric report card, and no minimum required levels for outcomes and supports have been identified. Instead, collaborative examination of this information will enable the Department and CCE PACE to identify and learn from areas of strength, and identify areas needing improvement. Although we cannot expect all outcomes, or any single outcome, to be present for all members, experience with these measures will, over time, provide a basis for reasonable expectations and comparisons. Most importantly, comparison of results over time will enable the Department, contractor, members, and others to determine whether improvement is taking place.

Additional Methods Help to Assure PACE Quality

Measuring member outcomes is only one component of a comprehensive quality assurance and quality improvement strategy for PACE. The contract between the Department and CCE PACE requires the identification of internal systems to improve, monitor and evaluate the quality of care provided to members. CCE PACE is required to conduct two quality improvement studies each year.

The Department also monitors CCE PACE's performance through self-reported measures that are tied to PACE outcomes. The Department also reviews required reports that are submitted by the contractor, including logs of complaints and grievances, reasons for disenrollment and quarterly utilization and narrative reports.

Additional department efforts include reviewing contract compliance by CCE PACE and analyzing the cost effectiveness of the PACE Program.

The Initial Measures of PACE Outcomes

The Department began working in July 2000 with the Council to develop a detailed strategy and work plan for assessing outcomes and supports. Critical elements for carrying out a reliable assessment of outcomes and supports included:

- **Devising the Interview Tool**. Focus groups including staff from the Department's BDDS and BALTCR reviewed the Council's interviewing tool and, in consultation with the Council, added questions for each outcome that were pertinent for each target group. The final Member Outcome Interview Tool, included in Appendix II, was used by the interviewers to guide their conversations with members and elicit the information necessary to determine whether the outcomes were present for each member.

- **Training and testing the interviewers**. Staff from BDDS and The Management Group, which works under contract with BALTCR, were trained in the Council's outcome-assessment techniques for elderly people and people with disabilities. After training, each interviewer was tested to ensure that inter-rater reliability (an indicator of the probability that any two interviewers would reach the same judgment in a given situation) reached a minimum of 85%. These interviewers conducted member outcome interviews for the Family Care and Partnership Programs before assessing outcomes for PACE members.

- **Selecting a random sample**. A random sample of 300 PACE members was drawn from the 425 plus enrolled individuals.

- **Arranging the meetings with members**. The individuals who were selected were contacted to request their participation, which was voluntary. Approximately 25% declined to participate because they were no longer in the program, had insufficient time, or medical reasons. For those who accepted, arrangements were made to carry out the conversation at a time and location of their choice, with any additional arrangements for special communication needs.

Over an eleven-week period from November 2001 to March 2002, 204 PACE members were interviewed about their individual preferences related to the 14 member outcomes. After interviewing both the member and his or her lead care manager, interviewers reached two determinations for each outcome: 1) was the outcome present in the member's life, and 2) was the contractor providing support for the achievement or maintenance of that outcome as defined by the member? A more detailed description of the methodology is included in Appendix II.

Results of the assessments

For each outcome, two results are reported: the percentage of interviewed members who reported that the outcome was present (quality of life), and the percentage of members for whom support for that outcome was found to have been provided by the contractor (quality of service).

Although each outcome has a generally defined content area, interviewers determined whether the outcome was present *as defined by each individual's own preferences*. For example, the outcome "People have privacy" has certain universal meanings, such as freedom from unwanted intrusions and dignity when being assisted with personal hygiene. However, some people like to be alone more often than others.

Supports were judged to be present if the lead care manager could demonstrate both that:

- The individual's preferred outcomes were known to the care management team, and
- Contractor staff were planning or carrying out actions that would achieve or maintain the outcome as defined by the individual.

Supports were considered to be provided only if the actions or services were designed around the outcomes as defined by the member, rather than being pre-defined standards or expectations that did not reflect the desired outcomes of the person being served.

These results document the initial levels of outcomes and supports.

The information presented in this report reflects the circumstances that were present at the time of the interview. Depending upon the desired outcomes and the member's capabilities, establishing the plan and services in place may take some time, and achieving the outcomes even longer.

For each individual, there are four possible combinations of outcomes and supports, shown below.

		Quality of Service	
		Support Present	Support not present
Quality of Life	Outcome Present	+	+
		+	–
	Outcome not present	–	–
		+	–

If both the outcome and the support are present (+ +), the person has defined his or her desired outcome and has found a way to achieve it. In addition, the contractor's professionals are aware of the person's desires and are assisting the person to

achieve them. It will be important that supports remain in place for the member so that any change in the member's needs or preferences will be reflected in the member's care plan.

If the outcome is not present, but the support is (– +), the person's desired outcome has been identified and the contractor's professionals are working to support it. However, a variety of circumstances may be preventing the achievement of the outcome. The person's capabilities might not yet be developed to the point where he or she can obtain the desired outcome. Some examples are:

- A person is in training for paid employment;
- Scheduled services or placements may be arranged but not yet implemented; and
- A person is on a waiting list for specialized housing.

In other cases, members may express desires for outcomes that are not attainable, such as desiring no support from family or friends or being reunited with a deceased spouse. In this case, the member's desired outcome will never be present, but the care management team can provide support to help the member with grief and with coping skills.

If the outcome is present, but the support is not (+ –), the person has defined his or her desired outcome and has found a way to achieve it. However, the contractor's professionals who are responsible for the person's plan of care may not be aware of the person's desires and may therefore be providing services that, while considered appropriate by others, may not be the most effective way to ensure the member's quality of life. It will be necessary for the care management team to become more responsive to the needs and preferences of the person—even in the absence of any expressed concerns or complaints by the individual—to ensure that the member's outcome remains present over time.

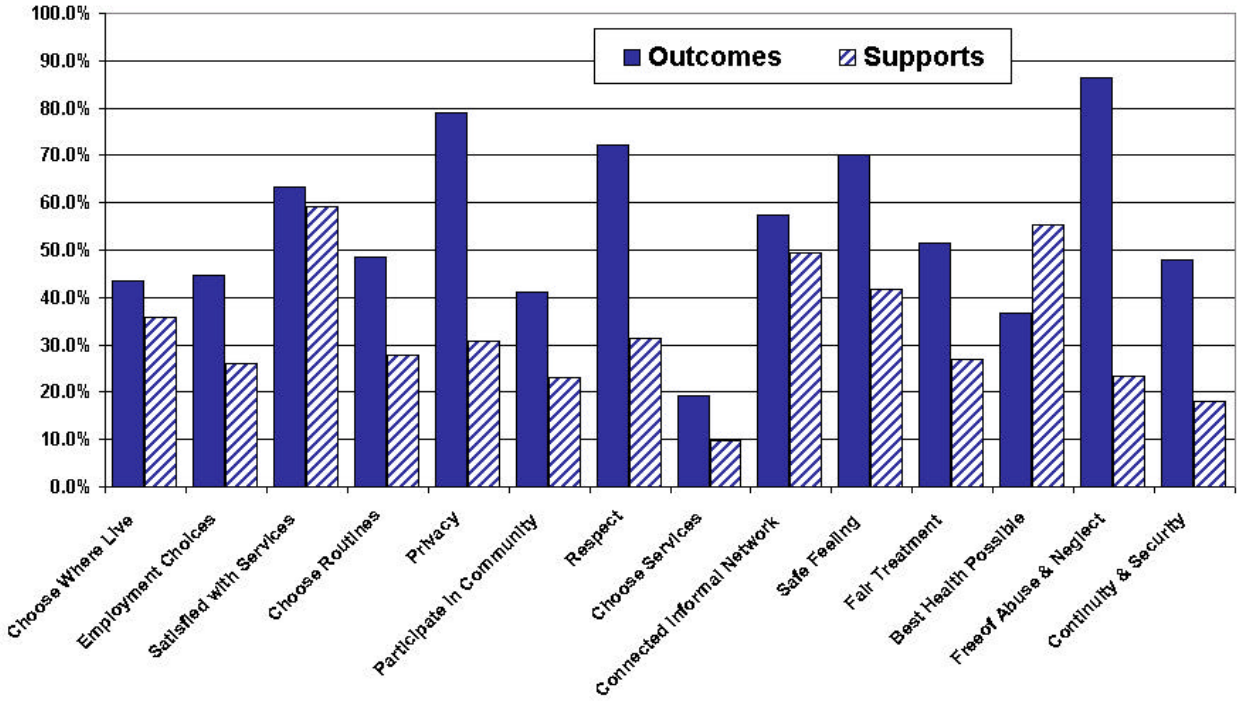
If the neither the outcome or the support is present (– –), the person may have preferences regarding the outcome but may not yet have found a way to achieve it. The person may not even be aware that his or her desires in the area are relevant to his or her care. In addition, the PACE professionals have not yet been responsive to the needs and preferences of the person, either because they are not aware of the person's needs and preferences or because they have not yet incorporated them into planning for the person's care.

Results Provide Direction for Quality Improvement Efforts

The following graph shows the results for each of the 14 outcomes. For each outcome measurement, there are two bars. The first, darker bar indicates the percentage of members for whom the outcome was present; the second, striped bar

indicates the percentage of members for whom the PACE contractor has in place a process to support the member's desired outcome.

CCE PACE Outcomes & Supports, Baseline Winter 2002, Sample of 204 People



The results from this initial assessment are lower than the initial assessments from Family Care or Partnership. Staff noted early in the interview process that they had limited knowledge of the member's home situation and thus were not providing much support for some of the outcomes. To better serve members, staff developed a tool to be used three times per year to assess the home environment and incorporate the findings into the care plan. Nursing and social work staff will be the primary disciplines making the home visits, however, occupational and physical therapy staff are available when the screening tool indicates the need.

DHFS and CCE PACE staff are looking at the differences between PACE and other long-term care programs in Wisconsin to help explain the disparity between PACE's outcomes and those of the other long-term care programs. When the PACE program first started, members were required to participate in the day program. That requirement no longer exists. However, some people may have entered the program while that requirement existed and their responses may have been affected by that requirement.

Another potential difference may be that when people enroll in PACE, they usually switch from their primary physician to the PACE program's physician but usually retain their specialists and hospital affiliation.

The three member outcomes related to integration within the community are being met by 62-78% of the members interviewed. Although the majority is achieving the desired outcome, almost a third are not. The Department and the contractor will discuss community involvement and participation with members and identify ways to provide supports for this outcome.

We do not yet know the attainment levels that can realistically be achieved for each of these outcomes (and it will differ by outcome). The Department and contractor can further analyze how certain living situations, age, or disability affect the attainment of outcomes.

The Department expects to identify performance benchmarks after additional data from PACE and other programs are accumulated. There are few programs serving a comparable population using an outcomes based assessment. Over time, the Department will be able to compare the assessments of outcomes and supports from different long-term care programs.

Results for each outcome

This chapter describes the meaning of each outcome and presents the outcomes present and supports provided in aggregate for PACE members. Appendix III contains the detailed information for each individual contractor.

Self-Determination and Choice Outcomes

1. People are treated fairly.

Each person is guaranteed the opportunity to be heard and treated fairly as an individual in any situation where limitations are imposed. Limitations may occur as the result of laws, community or group norms, or the needs of other people, but should be temporary. People have the right to expect that they will be informed of options, give consent to proposed actions, have their personal concerns be considered important, and have a fair and impartial hearing in disputes.

The outcome *is* present if:

- No rights limitations or fair treatment issues have been identified by the member; *or*
- Due process was provided to the member if there were rights limitations or fair treatment issues.

The outcome *is not* present if:

- Limitations have been imposed on the member, but the member has not agreed to the limitations, does not know why they were imposed, is unaware of any plan to change the limitation, or if due process to have the limitation lifted has not been provided; *or*
- The member is unaware of how to file a complaint if he or she experienced unfair treatment.

To support these outcomes, contractor staff should be aware of any rights restrictions or limitations imposed upon a member. They should provide members with training and support so that limitations are reversed or removed. The care manager should provide the members with access to a fair and impartial hearing of grievances and an independent review of limitations to personal freedoms. The contractor should review and change policy and practice that limit or restrict members.

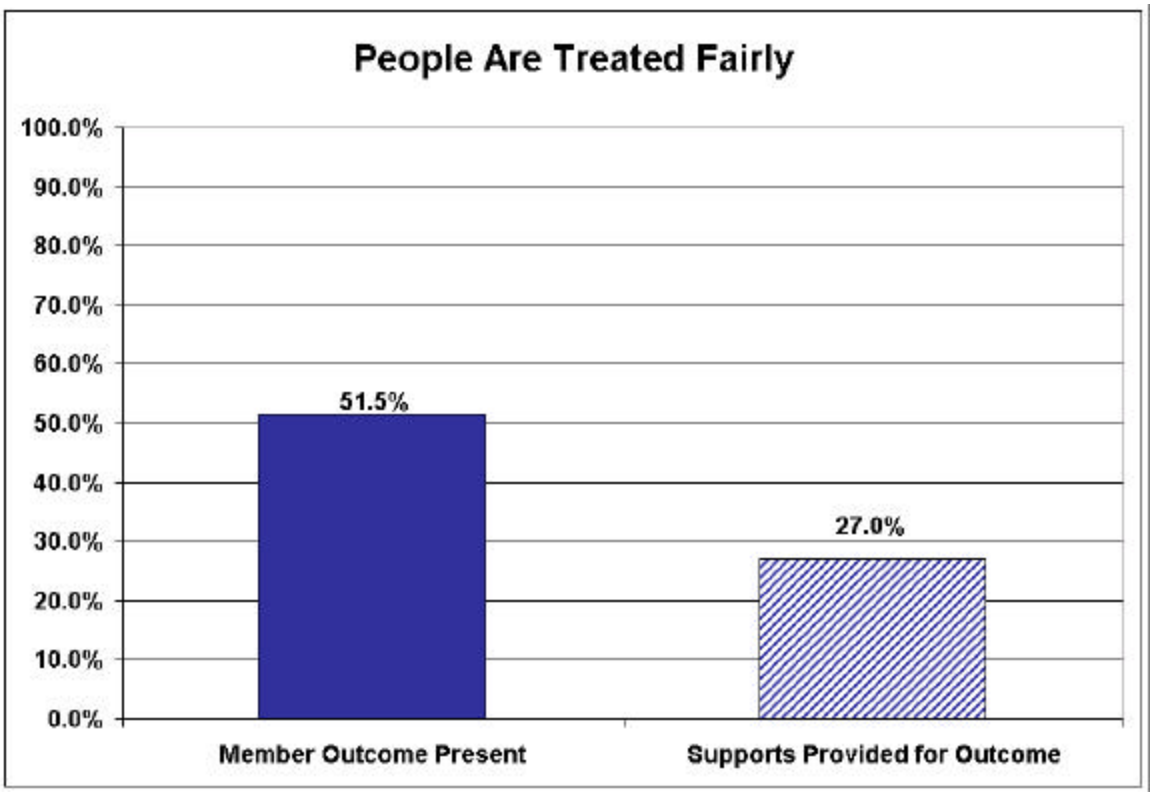
The support *is* present if:

- The care manager solicited information about rights violations or fair treatment issues from the member; *and*
- The care manager has implemented procedures for addressing the person's concerns.

The support *is not* present if:

- The contractor is not providing due process when limitations are imposed;
- The care manager is not aware of existing rights violations;
- There is no plan in place to remove existing restrictions; *or*
- The care manager has not asked the member about fair treatment.

This outcome was achieved for 51.5% of the interviewed members and supports were in place for 27.0% of the interviewed members. More than half of the members are experiencing fair treatment. Staff are identifying ways to insure that more supports are in place for members.



2. People have privacy.

Privacy is freedom from unwanted intrusion; each person has different requirements for privacy. People may need private space and time when talking on the telephone, reading mail, and being with friends, family, and others. When people live together, privacy is more complicated. It may not be possible for each person to have access to privacy at the same time. Privacy is particularly important when staff assists and support people with personal hygiene and health needs. Dignity and respect must always be demonstrated, and people should decide who provides this care.

The outcome *is* present if:
- The member has time during the day for private activities and general privacy;
- The member can go somewhere to be alone or with friends;
- Privacy is provided when the member desires or requests it; *and*
- The person is satisfied with the level of privacy offered.

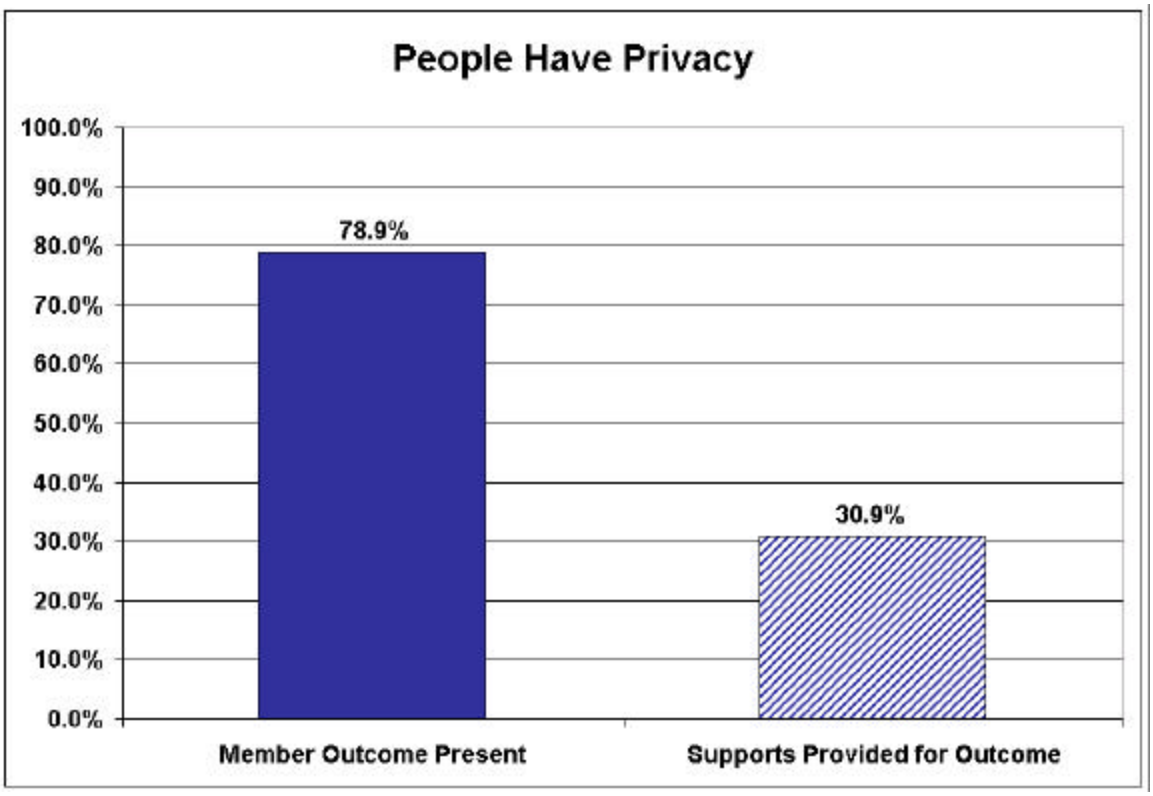
The outcome *is not* present if:
- The member is not provided privacy when requested;
- The member's behavior during personal time is not private;
- The member does not have space to be alone; *or*
- Personal hygiene or health needs activities are not conducted in a way to ensure dignity and respect.

To support these outcomes, the care manager should be aware of the member's need for privacy and his or her preferences regarding privacy. The care manager should ensure that the member has opportunities for privacy, particularly in settings where many people live together. The care manager should ensure that staff assignments to assist a person with personal hygiene reflect personal preference and sensitivity to the dignity of the person.

The support *is* present if:
- The care manager knows the member's preferences for privacy or is making efforts to learn about preferences; *and*
- If the accommodations are made to honor the member's preferences.

The support *is not* present if:
- The care manager is not knowledgeable about the member's preferences regarding privacy and is making no efforts to learn about them;
- The care manager does not have a plan to accommodate the member's preferences; *or*
- The care manager is not aware of the provider's procedure during personal hygiene activities.

Individual privacy outcomes were present for a majority of members (78.9%) even though supports provided were in place for just 30.9% of the interviewed members. The three times per year home visit will provide staff with information about the level of privacy that members experience. Department staff may also analyze this area further to determine if there is a correlation between living arrangement and outcomes being met for privacy.



3. People have personal dignity and respect.

Respect indicates that we believe that someone is a valued person. Respect is more than the absence of negative comments or actions. Respectful treatment and interactions enhance the person's self-esteem and result in positive perceptions by others. Respect is demonstrated by how people interact. Respect means listening and responding to the person's needs with the same promptness and urgency that anyone would expect.

The outcome *is* present if:
- The member reports feeling respected by others; *and*
- Interactions between the member and others reflect concern for the member's opinions, feelings, and preferences.

The outcome *is not* present if:
- Others are not calling the member by his or her preferred name;
- The member does not feel that his or her opinions are valued or that others are listening; *or*
- The member does not feel challenged in daily activities or encouraged to try new things.

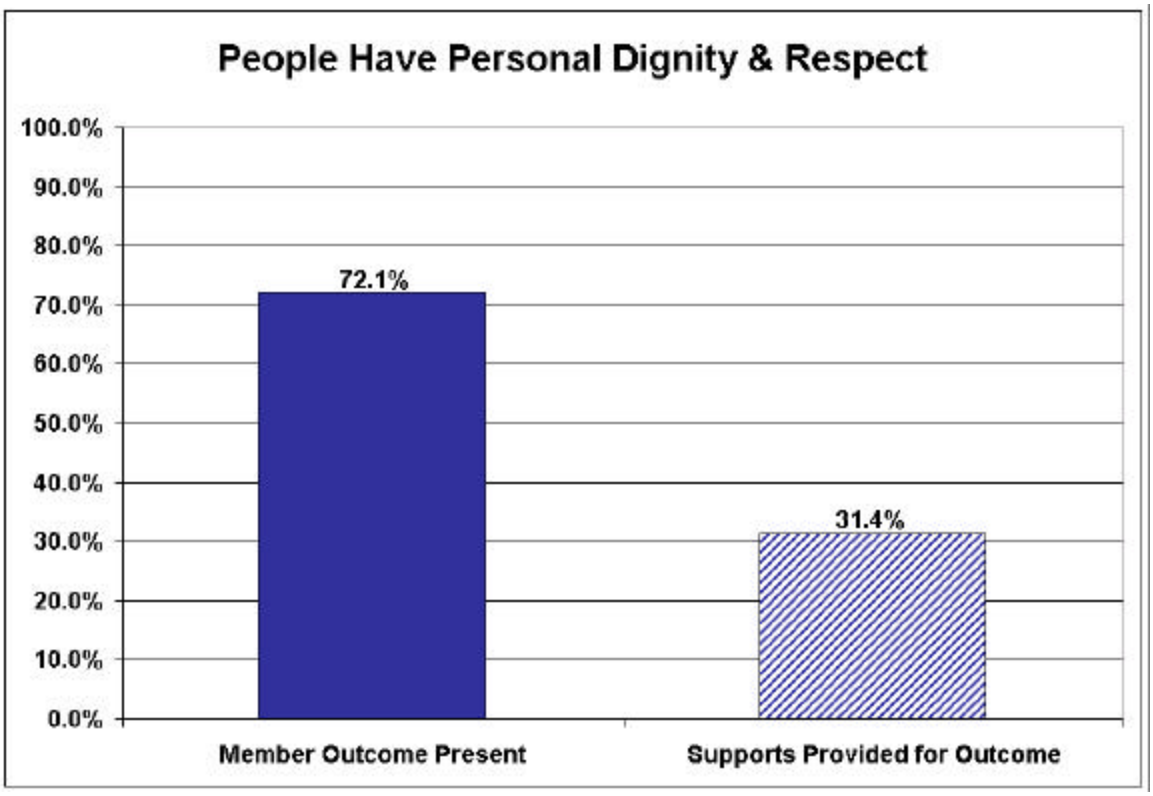
An isolated example of disrespectful interactions or practices would not automatically cause the outcome to be considered not present.

To support these outcomes, the care manager should be aware of the member's preferred name, and use it with respect for the person. Confidentiality should be exercised when speaking about the member. The opinions and preferences of the member should be included in the planning and decision making processes. The care manager should also display concern about the member's feelings and avoid anything that may cause the member any personal, physical or social discomfort.

The support *is* present if:
- The care manager knows what is important to the member with regards to respect;
- The care manager takes action to ensure the interactions with the member are respectful; *and*
- Supports needed to enhance the member's self-image have been identified and implemented.

The support *is not* present if:
- The care manager does not know whether the member feels respected and is not knowledgeable about the member's preferences regarding respect;
- The care manager does not have a plan to assist the member when he or she feels disrespected; *or*
- The care manager has not discussed respect with the member.

About 72% of members achieved this outcome and supports were provided for about one-third of the members interviewed. The outcomes achieved are similar to those achieved by the national accredited organizations in 1998. The supports provided were not comparable.



4. People choose their services.

Services exist to help people get what they want and need. The ability to choose where to shop, do business, or obtain services means that people are more likely to get what they want and need. Choice means offering options for services and interventions and respecting members' wishes. A person's ability to choose and make decisions regarding services changes throughout his or her life.

The outcome *is* present if:
- The member has choices about service providers;
- The member selected the services or supports that he or she receives; *and*
- The services or supports focus on the member's goals.

If the member did not originally choose his or her services, but has decided to maintain the current services after options have been presented, the outcome is present.

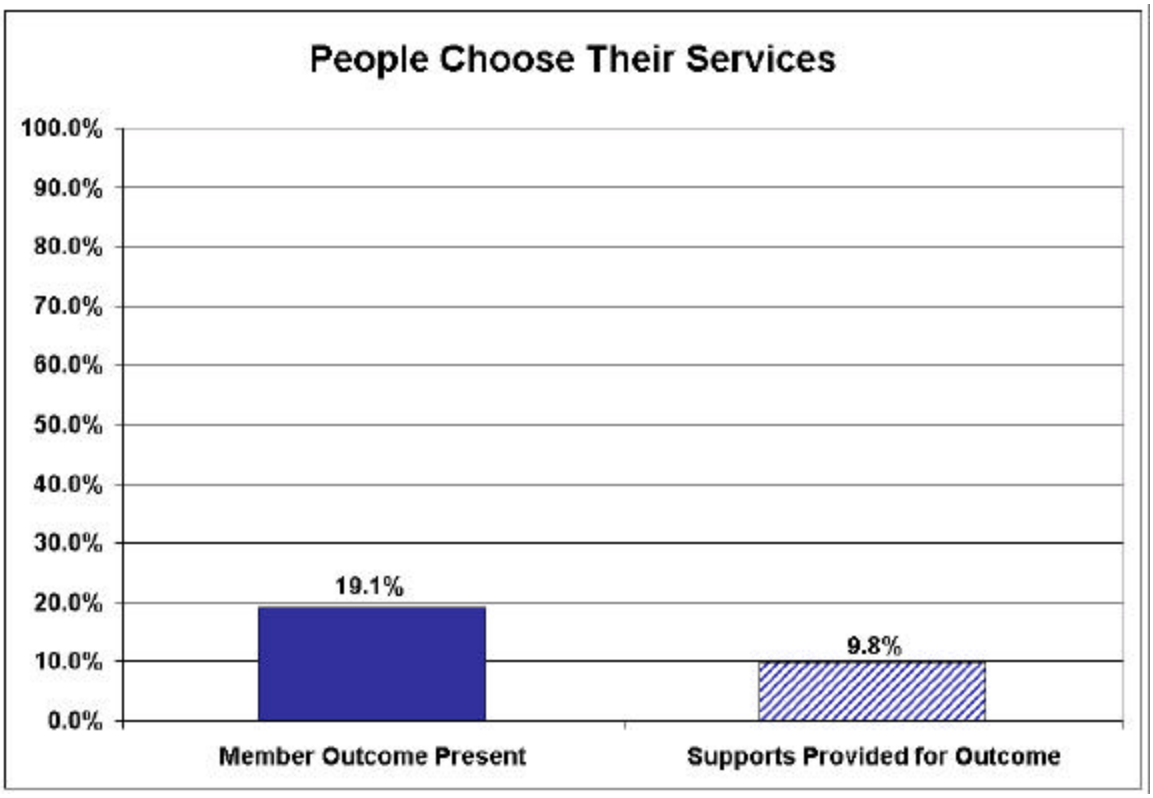
The outcome *is not* present if:
- The member has not been presented options of services;
- Has not been consulted when decisions were made regarding services; *or*
- Is not aware that he or she can change services.

To support these outcomes, the care manager should be aware of the member's preferences for services and provide choice of providers. The care manager should assist the member in gathering information, should discuss benefits and drawbacks of different services, and should visit the service setting and meet the employees. The care manager should not arrange services that do not match the member's preference. Options may be limited, but not because the care manager believes that the option may not be a good match for the member. The care manager should identify what decisions the member is able to make and should provide support to support or expand decision-making capability over time.

The support *is* present if:
- The care manager actively solicits the member's preferences for services and providers;
- The care manager provides options to the member about services and providers; *and*
- The member's choices about services and providers are honored.

The support *is not* present if:
- The care manager is not knowledgeable about the member's preferences;
- Service options have not been presented to the member;
- The care manager has not discussed choice of service with the member; *or*
- No plan is in place to address the member's preferences.

The outcome and support for "People choose their services" were present for 19.1% and 9.8% respectively. The PACE program model previously required the member to attend the PACE day program. That requirement no longer exists but some interviewees may have enrolled in the program while that requirement did exist. However, members do need to have a PACE primary physician but usually retain their specialists and hospital affiliation. Members may have viewed these requirements as a loss of choice. The Department and CCE PACE staff will discuss the issue of choice of services with members and identify ways to increase the percentage of members achieving this outcome and receiving supports for this outcome.



5. People choose their daily routine.

Being able to make choices about daily activities is basic to exercising personal control. People need to be able to make choices in organizing their personal routine of activities to express their individuality. Routine activities include choosing times for work, leisure, personal care, eating, and sleeping; making menu choices; selecting clothes for the day; and setting aside time to spend with family and friends.

The outcome *is* present if:
- The member had choice about what to do during the day; *and*
- The member chose when, where and for how long he or she would engage in routine activities such as household chores, meals, bathing, rest, recreation, and leisure activities.

The outcome *is not* present if:
- The member has not been provided with opportunities to make choices;
- Options have not have been presented to the member; *or*
- Routines have been dictated, or others living in his or her household overruled the member's choices.

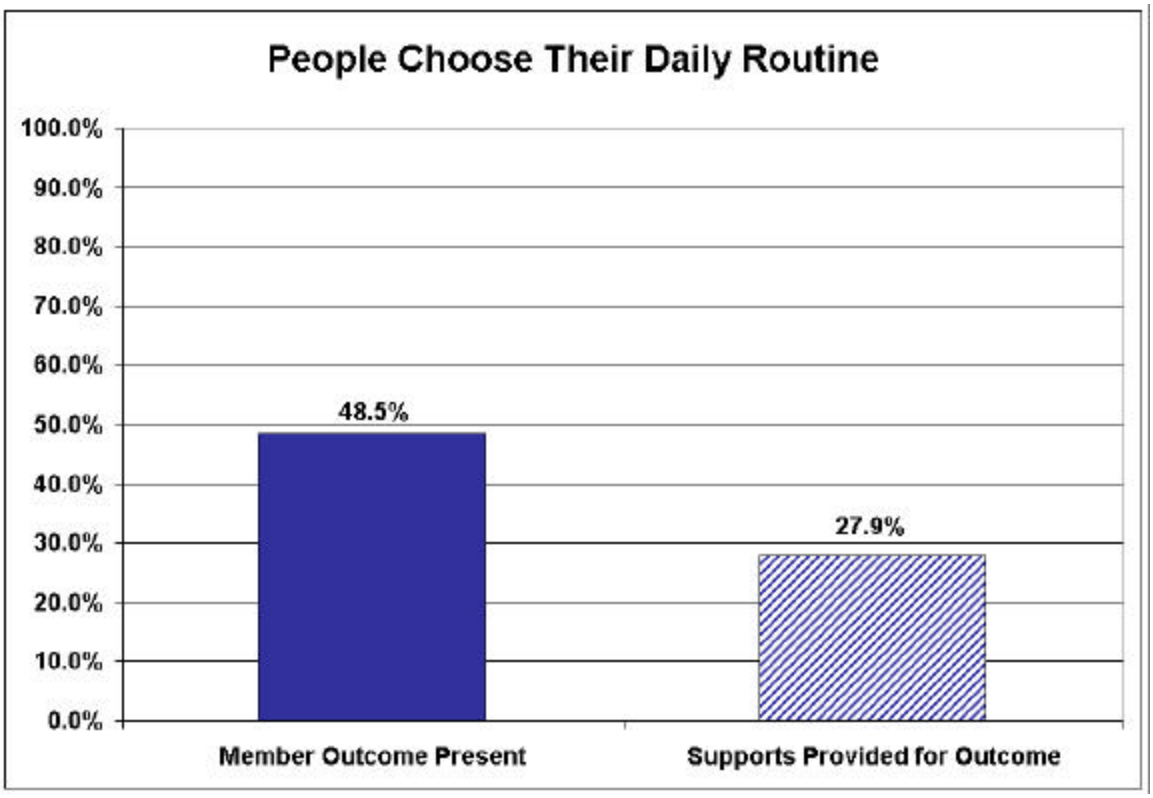
To support these outcomes, the care manager should be aware of the member's preferences with regards to his or her daily routine, and encourage the member to make decisions. The care manager should assist in working out compromises when the member resides in group setting and the preferences of the member conflict with those of others. The care manager should encourage providers to be flexible in order to accommodate changes that the members may request.

The support *is* present if:
- The care manager is knowledgeable of the member's preferences for daily routines; *and*
- The care manager or provider is making accommodations to honor the member's preferences.

The support *is not* present if:
- The care manager does not know who made the choices for the member regarding daily routines;
- The care manager does not know the member's preferences;
- The care manager has not offered options to the member;
- The care manager is not actively seeking ways to increase the opportunity for the member to make choices when options are limited; *or*
- The care manager is not actively planning for ways to accommodate the member's preferences.

The levels of outcomes achieved and supports provided for this outcome are likely affected by the prior requirement to attend and follow the schedule of the day

program. Members are no longer required to attend the day program. The three times per year home visit may provide staff with insight about the member's choice of daily routine and whether it's affected by access to transportation or availability of personal care services at different times of the day.



6. People achieve their employment objectives.

Finding and choosing a job and a career is an important life decision. People can have productive lives with or without paid employment, if they have meaningful activities that provide similar social and personal rewards. People should have the opportunity to consider a range of choices such as paid employment, volunteering, continued learning, or leisure activities.

The outcome *is* present if:
- The member has the opportunity to experience different options; *and*
- The member has decided where to work or what to do.

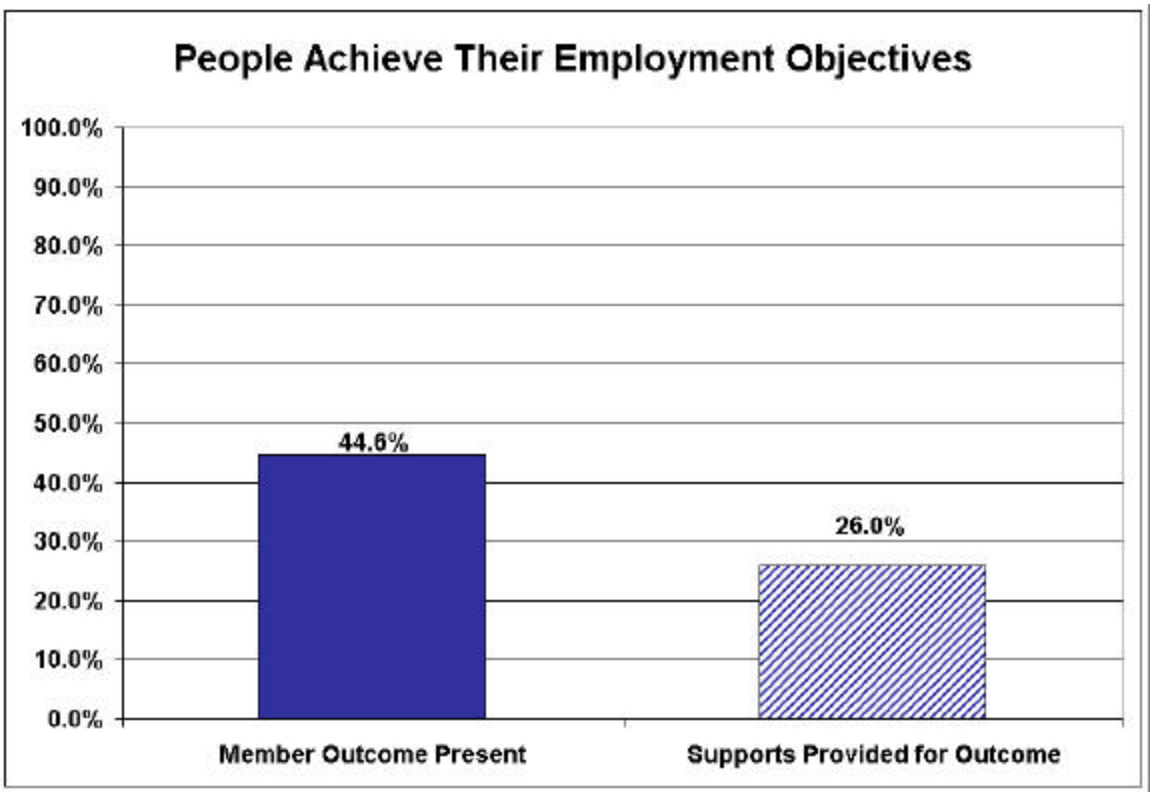
The outcome *is not* present if:
- The member wants to work but does not know how to access the job market;
- The member has not been presented with options of where to work;
- The member is not working in a preferred career or volunteer activity for a preferred contractor, or for the preferred hours; *or*
- The member does not have enough activities to provide him or her with a meaningful day.

To support these outcomes, the care manager should learn about the member's preferences, interests, and desires for work or meaningful activities and about the member's skills. If the preferred option is not available, the care manager should have a plan in place to assist the member in identifying the next best alternative. The care manager should help the member in locating assistive technology devices or supporting environmental adaptations.

The support *is* present if:
- The care manager knows the member's interest for work or is making efforts to learn what the member would like to do;
- The care manager provides the member with access to varied job experiences and options;
- The care manager responds to the member's desires for pursuing specific work or career options with supports; *and*
- The care manager supports the person in addressing any identified barriers to achieving the outcome of where to work.

The support *is not* present if:
- The care manager does not know who made the choices regarding the member's work situation;
- The care manager does not know the member's desires for working situations;
- No plan is in place to address the member's preferences or barriers with regards to work; *or*
- The member has not been provided with options for work or meaningful activities.

Almost one half of members achieved their employment objectives, even though only a fourth were found to be receiving support for their desired outcome in this area. Further data review and discussion with members by the contractor may help staff learn more about what factors contribute to attainment of this objective.



7. People are satisfied with services.

Satisfaction as defined by the person is a key to quality of services and supports. Satisfaction is related to what people think of services and supports, what their expectations are, and what else they want for the future. Satisfaction does not necessarily mean getting everything you want, but it is more likely to occur when people feel that they are seen as important and treated with respect. The absence of a complaint does not mean the member is satisfied.

The outcome *is* present if:

- Services and supports are provided to meet the member's expectations and needs.

The outcome *is not* present if:

- The member perceives a gap between expectations and what is actually happening;
- The contractor is not able to provide all needed services to the member;
- Options have not been presented; *or*
- The member has lodged a complaint that has not been addressed to his or her satisfaction.

To support these outcomes, the care manager should solicit the member's opinions about services and supports and respond to what is learned. The care manager should anticipate the need to modify services and supports as the member grows or changes over time. Options for changing services and supports should be provided if the member expresses dissatisfaction.

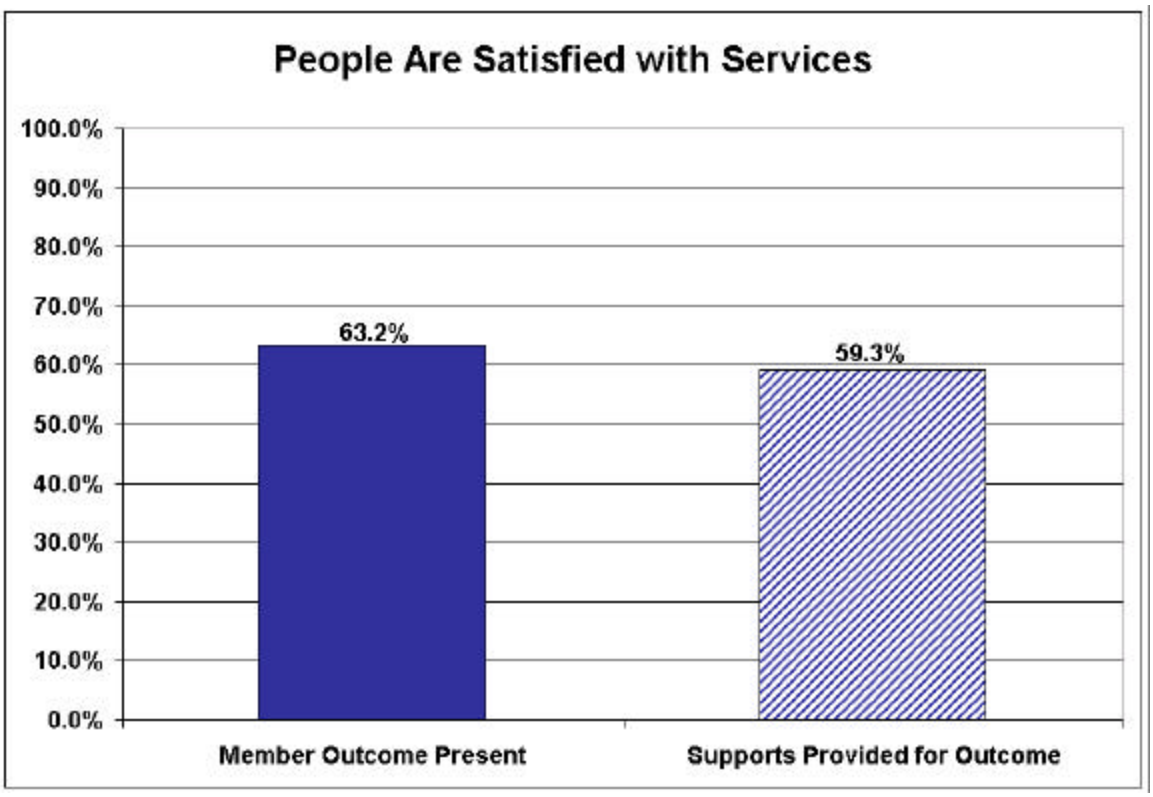
The support *is* present if:

- The care manager actively solicits the member's opinions about services and supports;
- The care manager responds to the member's feedback regarding supports and services; *and*
- Changes or modifications are made to increase the member's satisfaction.

The support *is not* present if:

- The care manager does not know the member's opinions regarding services or supports;
- The care manager is unaware of specific issues with providers; *or*
- There is no plan to implement changes if the member is dissatisfied.

The percentages for outcomes achieved and support provided were fairly close and relatively high at 63.2% and 59.3% respectively. The Department and staff may look to determine if there is a relationship between "choosing services", "choosing daily routine" and "satisfaction with services".


People Are Satisfied with Services
100.0%
90.0%
80.0%
70.0%
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
63.2%
59.3%
Member Outcome Present
Supports Provided for Outcome

Community Integration Outcomes

8. People choose where and with whom they live.

Choice of a living situation is important in all people's lives. People should be able to choose their living arrangement, location, and the person with whom they live if they prefer to live with others. People need opportunities to see what is available and to make informed choices.

The outcome *is* present if:
- The member was provided with options about where and with whom to live;
- The member decided where to live; *and*
- The member selected with whom to live.

If the member did not originally choose his or her living situation, but decides to remain there after options have been presented, the outcome may be met.

The outcome *is not* present if:
- Decisions of where or with whom the member will live have been made by others without the member's own choices being solicited and considered;
- Options are limited due to lack of accessibility; *or*
- The member is not living where he or she wants to live or with whom he or she would like to live.

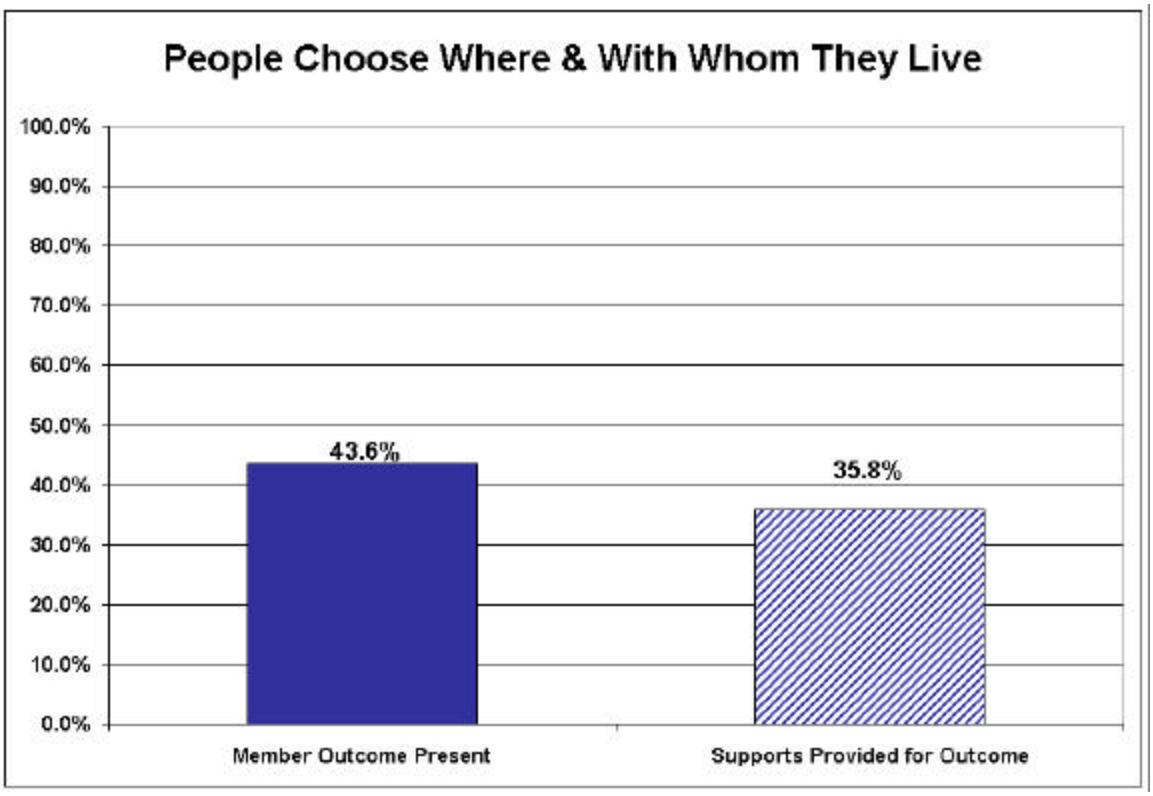
To support these outcomes, the care manager should be aware of the member's preferences in living situations and should inform the member of available options. When options are limited for reasons such as local availability, the care manager should have a plan in place to achieve the outcome, and assist the member in finding the next best situation, including making changes to the member's current living situation. The care manager should also look at ways to reduce financial or regulatory barriers so that more options become available.

The support *is* present if:
- The care manager knows the member's preferences about where and with whom to live;
- The care manager is supporting the member in exploring options and in making informed decisions; *and*
- The care manager acknowledges the member's preferences and supports him or her to address any barriers that prevent the member from living where and with whom he or she wants.

The support *is not* present if:

- The care manager does not know who made the choices regarding the member's living situation;
- The care manager does not know the member's preferences;
- No plan is in place to accommodate the member's preferences; *or*
- Options have not been explored with the member.

Although 43.6% of the interviewed members achieved their desired choices of where and with whom to live, supports were present for a smaller percentage—35.8%. The three times per year home visit will be an opportunity to explore whether members are living where and with whom they wish to live. Department staff can also identify the impact of living arrangement on achievement of this outcome.



9. People participate in the life of the community.

The community has many resources for personal support, enjoyment, and personal development. When people go out in the community they meet other people, learn, and broaden their experiences. Generic community resources, such as doctors, restaurants, banks, grocery and retail stores, should be the preferred choice for health, leisure, and routine daily living activities.

The outcome *is* present if:

- The member is aware of the options available to all others in the community; *and*
- The member indicates that the type and frequency of participation in the community is satisfactory.

If the opportunities for the member to participate in the life of the community are limited only by the community size and location, then the outcome is present as long as the member is aware of the limited opportunities available.

The outcome *is not* present if:

- The member is not participating in the community as much as he or she would like to; *or*
- The member has not been able to attend an activity he or she would like to due to lack of available transportation or staff to assist the member, or because the member could not afford the cost of the activity.

To support these outcomes, the care manager should be aware of the member's preferences and interests regarding type and frequency of community activities, provide information about and access to community activities and resources, and provide assistance with transportation if needed. The care manager should tailor supports according to each member's interests and preferences regarding community activities.

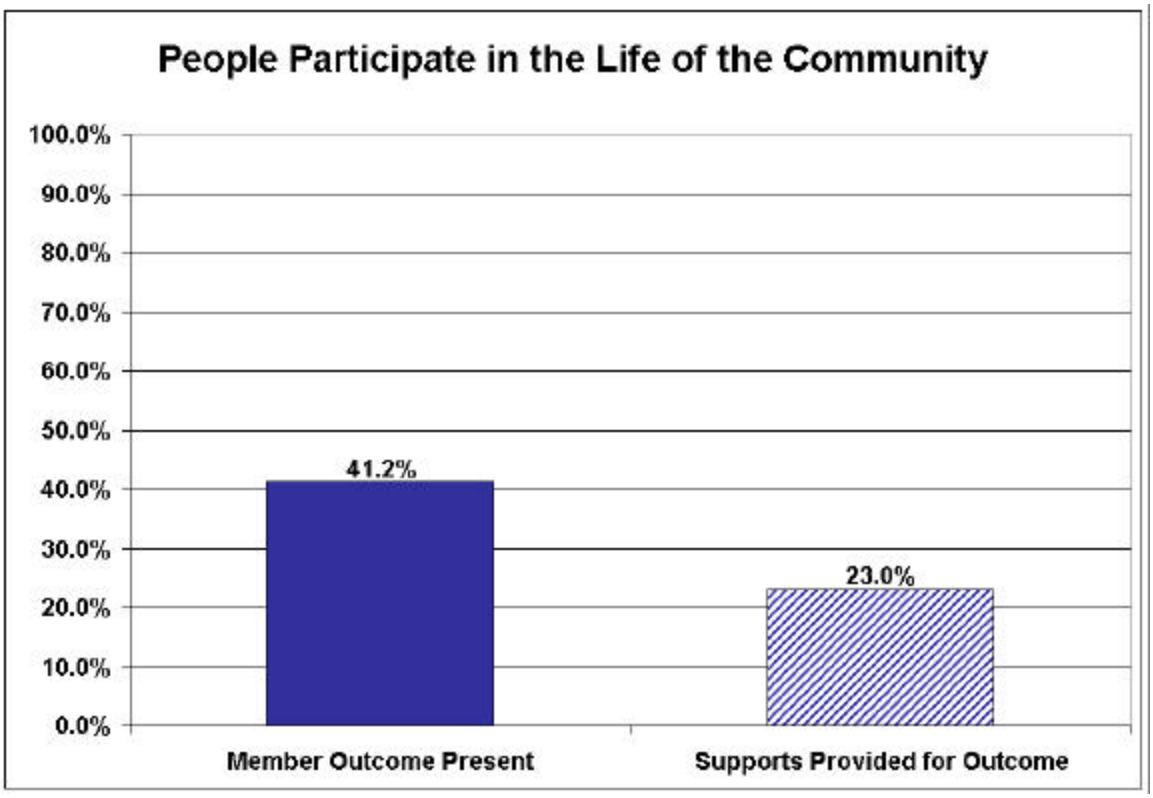
The support *is* present if:

- The care manager knows the member's preferences regarding type and frequency of community participation or is making efforts to learn about the member's preferences;
- The care manager provides information about options for community participation; *and*
- The care manager provides support to the member to do the things he or she would like to do.

The support *is not* present if:

- The care manager does not know the member's preferences regarding type and frequency of community participation and is not making efforts to learn them;
- The care manager has not provided information on options for activities or transportation services; *or*
- The care manager is not assisting the member by addressing staff shortages or financial barriers.

The levels of outcomes present (41.2%) and supports provided (23.0%) for this outcome are lower than most of the other PACE outcomes and lower than those for the national accredited organizations. It will be important for the PACE staff to focus on what barriers exist to prevent members from participating in the community as much as they would like and to develop strategies to overcome these barriers.



10. People remain connected to informal support networks.

Informal support networks are groups of people, such as family and close friends, whose support of each other is usually lifelong and results in security and the provision of a safety net to the person. Informal support cannot be created or manufactured, but can be nurtured as people and relationships grow and evolve. Time, age, and distance can affect how well people remain connected.

The outcome *is* present if:

- The member is in contact with people who provide informal support as frequently as is satisfactory to the member; *or*
- The member does not have an informal support network due to personal choice or natural circumstances.

The outcome *is not* present if:

- The member desires more or less contact with people who provide informal support; *or*
- The member is not receiving needed assistance in contacting people who can provide informal support.

To support these outcomes, the care manager should be aware of the member's informal support network and the member's preferences for staying involved. If the member desires, the care manager should assist the member in re-establishing contact with family members and developing and maintaining an informal support network.

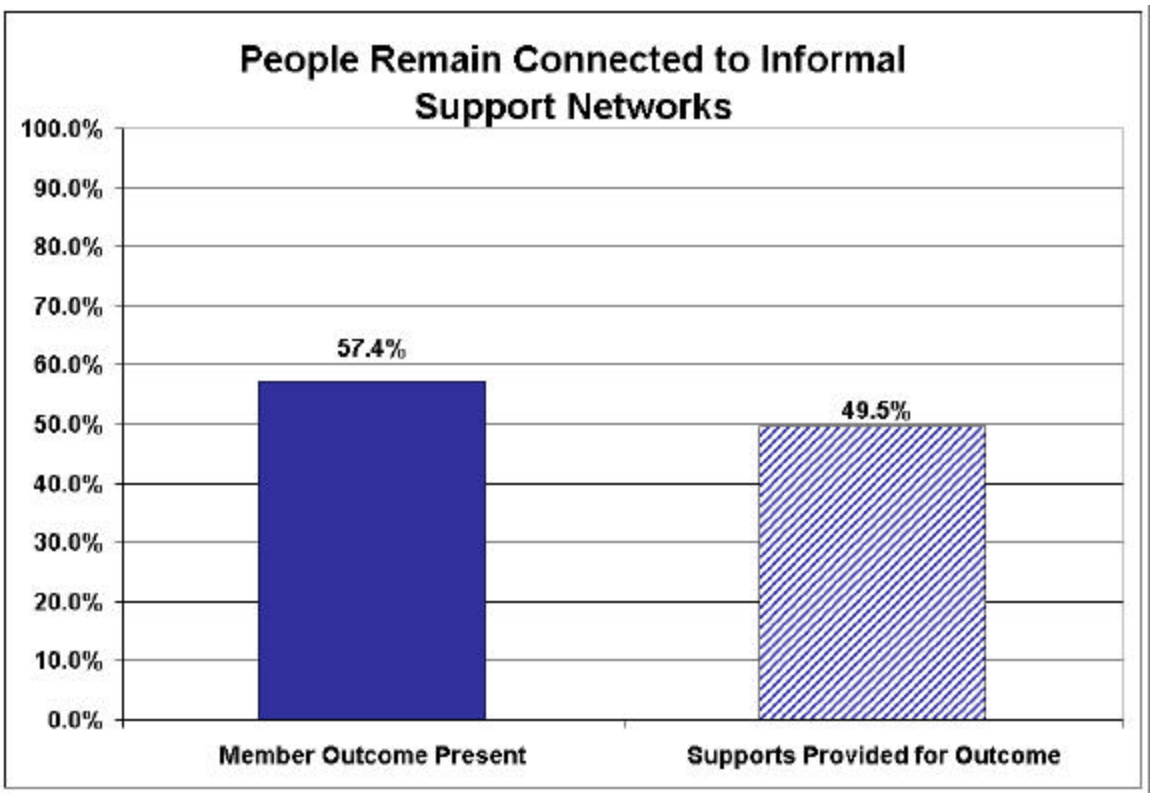
The support *is* present if:

- The care manager can identify the member's informal support network;
- The care manager knows the status of relationships within the informal support network; *and*
- The care manager provides support for the member's relationships within the network if needed and requested.

The support *is not* present if:

- The care manager does not know who provides informal support to the member;
- The care manager does not have a plan to assist the member in maintaining the contact with people who provide informal support; *or*
- The care manager is not aware of the member's need to contact people who provide informal support.

The percentages for outcomes achieved (57.4%) and supports provided (49.5%) are lower than those of other long-term care programs. Further investigation may look at how the age or disability of a member may affect the informal support network.


People Remain Connected to Informal Support Networks
100.0%
90.0%
80.0%
70.0%
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
57.4%
49.5%
Member Outcome Present
Supports Provided for Outcome

Health and Safety Outcomes

11. People are free from abuse and neglect.

Treating people with dignity and respect requires that they are free from abuse and neglect. Actions and practices that may constitute abuse and neglect need to be functionally defined and understood. Abuse is defined and measured according to the person's experience, regardless of when it occurred.

The outcome *is* present if:

- There are no allegations of abuse or neglect by or on behalf of the member;
- There is no evidence that the member has been abused, neglected or exploited; *and*
- The member is not experiencing personal distress from a previous occurrence of abuse.

The outcome *is not* present if:

- The member has reported any allegation of abuse or neglect or there are indications of abuse or neglect;
- The member is experiencing personal distress from a previous occurrence of abuse; *or*
- The member is unaware of the reporting procedure for abuse and neglect.

To support these outcomes, the care manager should define and expressly prohibit abuse and neglect. The care manager should develop a program of supports to prevent situations conducive to abuse and neglect. Such programs could train members and staff to recognize and report any suspected incidents of abuse and neglect. The care manager should also implement policies and procedures for initiating intervention and investigation in all alleged cases of neglect or abuse, within or outside of the contractor.

The support *is* present if:

- The care manager knows the member's concerns regarding abuse or neglect;
- The care manager provides the member with information and education about abuse and neglect; *and*
- The care manager provides support for the member if he or she has expressed concerns about, or if there have been occurrences of, abuse or neglect.

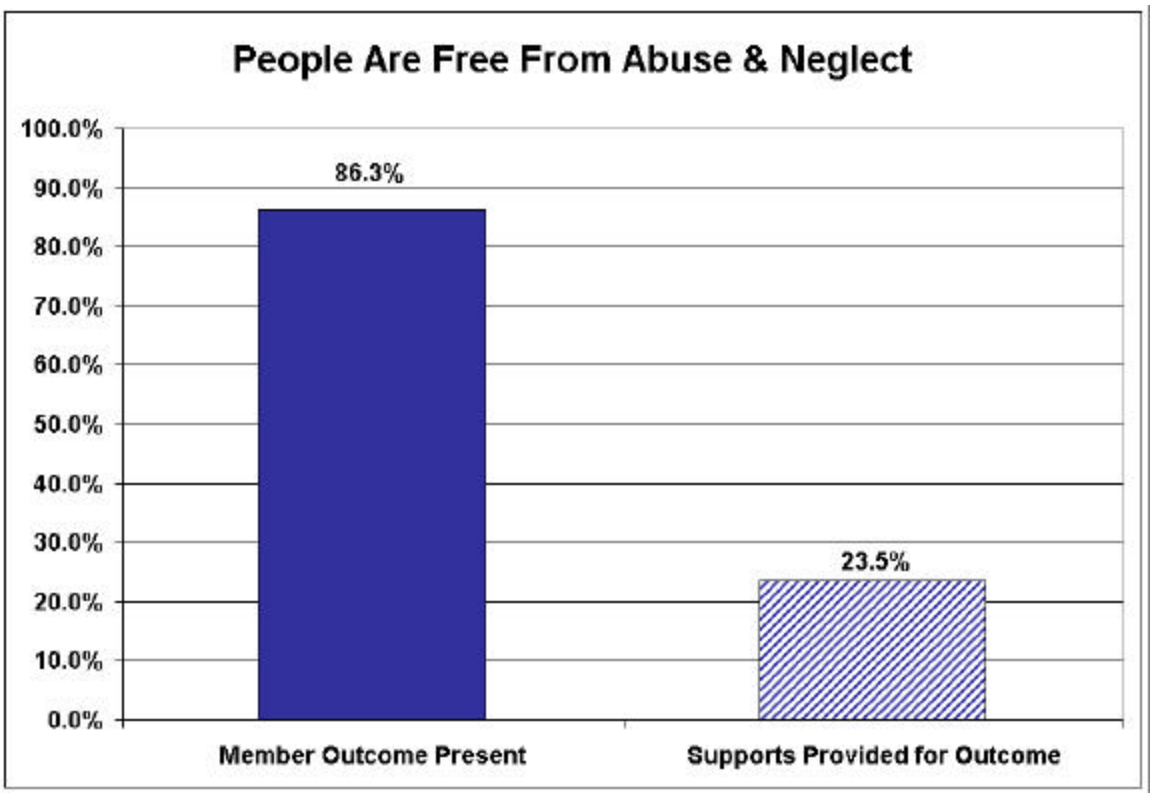
The support *is not* present if:

- The care manager does not know whether the member has concerns regarding abuse or neglect;
- The care manager has not provided the member with training and education regarding abuse or neglect; *or*
- The care manager has no mechanism to provide intervention in situations where staff suspects that the member is or may be at risk for harm.

For this outcome, the difference between outcome achieved (86.3%) and support provided (23.5%) is extremely large. Early discussions with the PACE care managers revealed a tendency by staff to limit their involvement to the member's participation in the day program. After reviewing the findings, staff have initiated discussions with the member about his/her current and preferred lifestyle and living arrangement.

Member outcome interviews for Wisconsin's Family Care program, another long-term care program, found a similar discrepancy between outcomes and supports. Initial discussions with care managers in the Family Care program indicate that care managers may be hesitant to broach this subject with members in the absence of evidence or complaints. However, even in the absence of signs of problems, care managers can more actively seek information about each member's perceptions to ensure that members remain free from abuse and neglect.

It should be noted that interviewers had been instructed, if they noticed immediate health or safety problems during their conversations with members, to ensure the safety of the member by taking any immediate action necessary to protect the member and to bring the problem promptly to the care manager's attention.


People Are Free From Abuse & Neglect
100.0%
90.0%
80.0%
70.0%
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
86.3%
23.5%
Member Outcome Present
Supports Provided for Outcome

12. People have the best possible health.

Best possible health must be defined in terms that are satisfactory to the member. The definition of "best possible health" depends on the current health status of the member and the possibility of health interventions to restore lost capacity, provide stabilization or minimize further loss of function. Health care interventions should be personalized and effective. Frail elderly people and people with disabilities should have access to health care services of the same variety and quality available to others.

The outcome *is* present if:

- The member sees a health care provider regularly;
- Health care professionals have identified the member's best possible health; and are addressing any health care issues, or concerns, and interventions;
- Health intervention services were selected by the member in consultation with the health care professional;
- Health intervention services as desired by the member have been effective; *and*
- The member has needed devices or equipment such as glasses, hearing aids or dentures that are in good repair.

If any of the above are not present as the result of the member's personal choice, the outcome may still be present.

The outcome *is not* present if:

- The best possible health situation for the member has not been identified or met;
- Health interventions have not been defined in collaboration between the member and a health care provider; *or*
- Needed devices or equipment are not available or are in bad repair.

To support these outcomes, the contractor should define best possible health that is satisfactory for the member. The care manager should provide the member with choices among health care providers and education about the availability of providers and services. Members should be provided with access to preventative screening and diagnostic testing, and with support towards self-managing and directing their own health care.

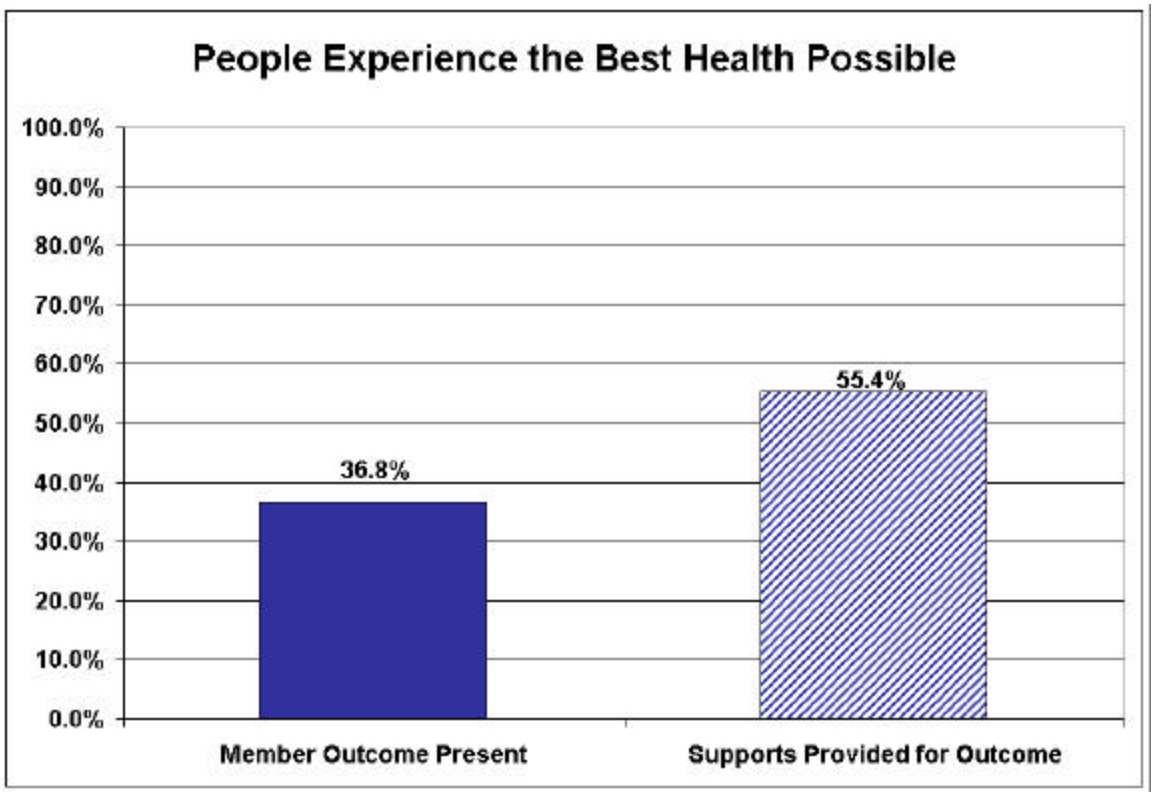
The support *is* present if:

- The care manager knows the member's defined best possible health;
- Any supports that the member needs and has requested to promote and maintain best possible health have been provided; *and*
- The care manager responds to the member's changing health needs and preferences.

The support *is not* present if:

- The care manager does not know the member's defined best possible health;
- No mechanism exists to promote or maintain the member's best possible health;
- The care manager is not responsive to the changing health needs and preferences of the member; *or*
- The care manager does not support the member in obtaining regular medical and dental services.

The percentage of outcomes present for "People have the best health possible" is second lowest of all the PACE outcomes. The support provided for this outcome is considerably higher. It will be worthwhile for the Department and contractor to analyze this outcome further to identify the reasons for the differences between support provided and outcome achieved. Possible reasons include the quality of services, or the member's age, disability or choice to comply or not comply with the recommended plan to improve their health.



13. People are safe.

Each of us needs to feel safe from danger in our homes, workplaces, neighborhoods, and communities. People rely on regulations and inspections to ensure standards are met in certain settings to ensure safety, and they rely on personal actions (such as installing smoke detectors or security alarm systems) to feel safe in other settings. However, normal environments contain a reasonable amount of risk, and overprotection can prevent people from leading a fulfilling life.

The outcome *is* present if:

- The member lives, works, and pursues leisure activities in environments that are safe;
- The member knows how to respond in the event of an emergency situation; *and*
- Assistance is available to a member who cannot evacuate independently in emergency situations.

The outcome *is not* present if:

- The member does not have working smoke detectors or fire alarms, a fire escape plan, or working emergency alert devices (for example, LifeLine);
- The member does not feel safe in the neighborhood; *or*
- The member does not know what to do in the event of an emergency.

To support these outcomes, care managers should be aware of the member's preferences regarding safety and should make attempts to ensure the member's safety. The contractor should address all safety concerns, even when the member may not fully recognize the dangers or hazards. Members should receive assistance in anticipating, recognizing, and taking care of safety issues.

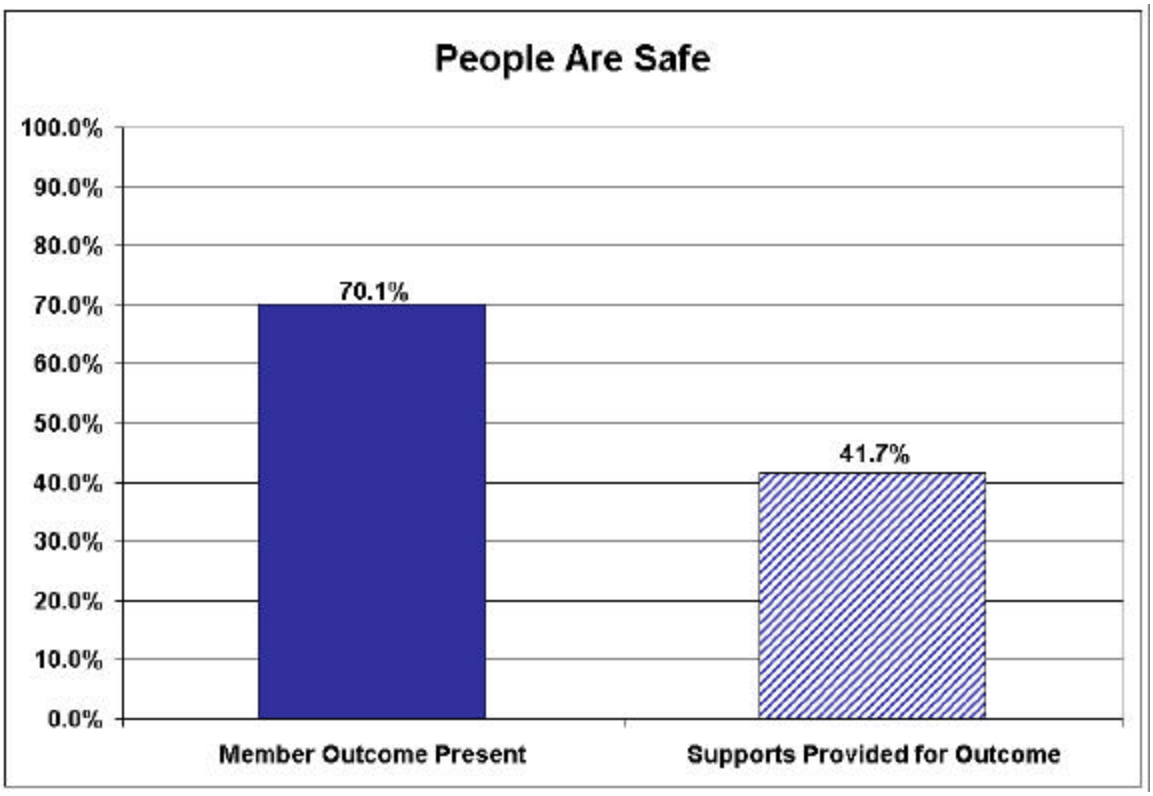
The support *is* present if:

- The member's safety issues have been identified; *and*
- The member has been provided with supports to address safety concerns if needed and requested.

The support *is not* present if:

- The care manager is not aware of the member's preferences regarding safety or whether the member knows how to respond in emergency situations;
- No plan is in place to address identified safety concerns;
- The care manager does not know whether the safety equipment in the member's home is in working order; *or*
- Safety issues have not been discussed with the member.

The levels of outcomes present (70.1%) and supports provided (41.7%) for this outcome are higher than some of the other outcomes but not as high as observed in the other long-term care programs. Compared to the locations of the other long-term-care programs, this program serves people who are in a higher risk area for safety considerations. Outcomes might be present more often than supports are provided because care managers may place less attention on safety when the member is in a regulated setting, trusting that the operators of the regulated setting will ensure safety. However, care managers and other team members can routinely ask members about their safety and discuss precautions such as good door locks, lighted entrances, and walking in well-lit areas. The three times per year home visit will be an opportunity to assess and address safety issues.



14. People experience continuity and security.

Change can contribute to happiness or discontent. Understanding and recognizing the emotional impact of change on a member is vital to providing member-centered services and supports. Economic security plays a significant role in enabling members to plan for the future. People should be included in all relevant decisions that impact their lives.

The outcome *is* present if:

- Changes experienced by the member over the past one to two years have been planned and controlled by the member or have not been upsetting to the member;
- The member's control over changes is similar to that exercised by other people; *and*
- The member has economic resources to meet his or her basic needs.

The outcome *is not* present if:

- The member has not been involved in planning for the changes;
- Changes were not based on the member's personal goals;
- The member does not have insurance or a plan to cover belongings in case of fire, theft, flood, or other losses;
- The member does not feel financially comfortable; *or*
- The member has been experiencing a lack of continuity of staff providing services.

To support these outcomes, the care manager should seek to understand how the member defines and reacts to change. The care manager should involve the member to the best of his or her ability in making decisions. The care manager should also take measures to ensure that member's economic resources are protected.

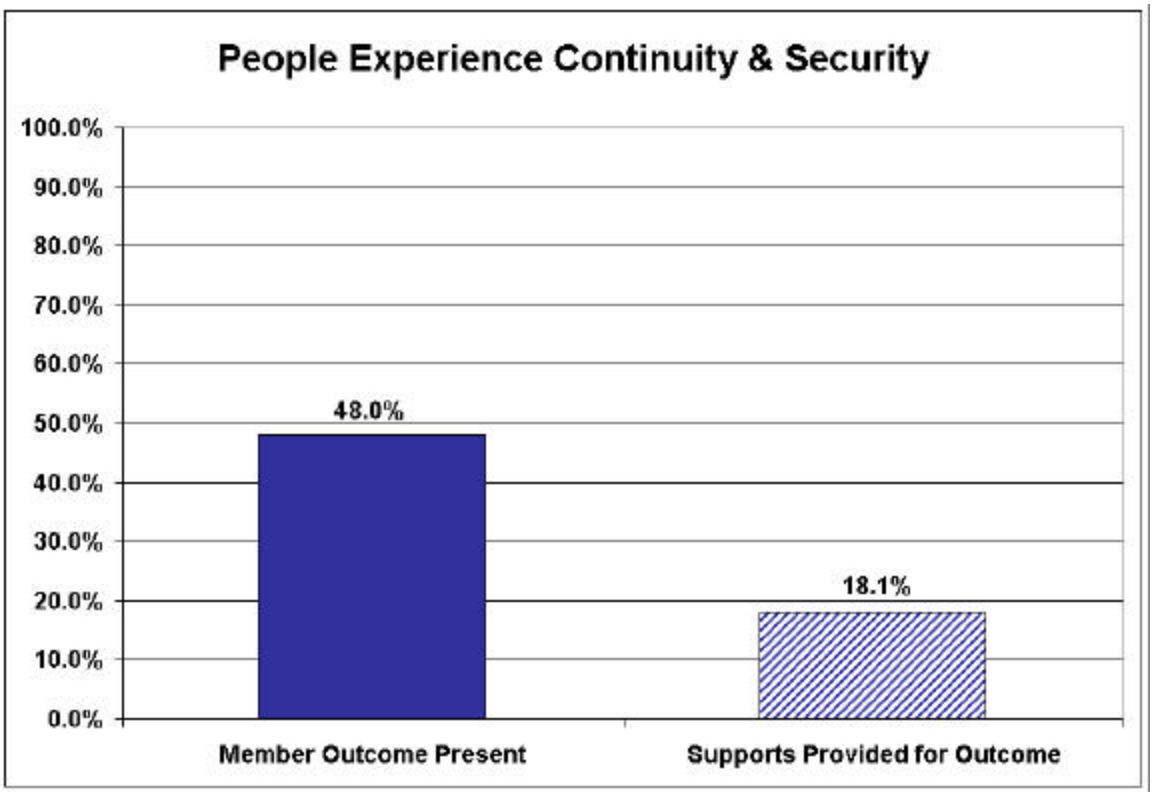
The support *is* present if:

- The care manager knows what the member requires to experience continuity and security or is demonstrating efforts to learn about the member's preferences; *and*
- The care manager has been providing support to the member in attaining and maintaining continuity and security.

The support *is not* present if:

- The care manager does not know the member's needs and preferences regarding continuity, security, and financial resources;
- No plan is in place to support the member in attaining and maintaining continuity and security; *or*
- The care manager does not know whether the member has insurance to cover belongings or a burial trust.

As noted, both outcomes and supports were lower for "People experience continuity and security" than for any other outcome in the PACE program. The desired outcome was present for only 48.0% of members and supports were present for just 18.1% of members. This particular outcome may rely too heavily on economic "insurance" to cover losses to remain secure. Interviewers' comments occasionally noted that people did not have renter's insurance or a burial trust, and that the case managers were unaware of the member's concerns. Further investigation by the Department and by the contractor will shed additional light on these results and provide guidance for improvement.



The Next Steps

This information does not provide a report card of the contractor's performance—it is too soon and we do not yet have the basis for establishing benchmarks or expectations. The information in this report is only a starting point. Over the next several months, Department staff will visit the PACE contractor to discuss how this information can be used most effectively in pursuit of quality for PACE members. The information from the member outcome interviews will provide important context for other quality assurance efforts, such as the review of individual service plans, and review of performance improvement plans.

The PACE contractor will receive and be able to use the outcome assessments of its members to evaluate its own performance. Consumers and long-term care advocates will also have access to summary data—without personal identifiers to preserve confidentiality—about the outcomes of people enrolled in PACE.

The initial data will provide a basis for comparison for future assessments. A second series of outcome assessments, with a separately selected sample of contractor members, will likely next year. As we accumulate perspective over time, the results for each contractor will be compared to their previous results, with national data, and with each other.

The PACE outcomes will be compared to those that will be assessed among participants in other programs. The Department is planning to use this method of assessing member outcomes among people in other programs such as the Medicaid Home and Community-based Waiver programs. Over time, the Department hopes to use the information gathered from the member outcome assessments to discern organizational, service, or support characteristics that are associated with the best possible outcomes.

More importantly, we hope that focusing on member outcomes will promote consistent attention at all levels to our ultimate purpose: improving the quality of life for people who need the services. At the local level, outcomes-focused care managers and providers will listen to the individuals who receive the services and find flexible, creative ways to provide support for their desired outcomes. At the Department level, outcome-focused staff will find ways to identify and share best practices among local programs to assist them in meeting equally high levels of performance. Outcome-focused state and federal policy makers will be able to direct resources to the most cost-effective programs and priorities.

Finally, looking forward to a time when long-term care members are able to exercise more choices among service providers, the Department intends that member outcome information will help those individuals and their advocates locate and select the best to help them.

Appendix I: An Overview of PACE

PACE is unique. It is an optional benefit under both Medicare and Medicaid that focuses entirely on older people, who are frail enough to meet their State's standards for nursing home care. It features comprehensive medical and social services that can be provided at an adult day health center, home, and/or inpatient facilities. For most members, the comprehensive service package permits them to continue living at home while receiving services, rather than be institutionalized. A team of doctors, nurses and other health professionals assess participant needs, develop care plans, and deliver all services that are integrated into a complete health care plan. PACE is available only in states that have chosen to offer PACE under Medicaid.

The primary motivation for replicating the PACE Program in Wisconsin was to provide a more responsive health and long-term care system for Wisconsin citizens – to provide both better access and higher quality services. The ultimate hope was that the integration of Medicare and Medicaid services would prove cost-effective by controlling expensive emergency, acute, and institutional care.

A key component of the PACE Program model is team-based care management. Under this arrangement, the participant, primary physician, and a team of nurses and social workers develop a care plan together. The team coordinates all service delivery.

To participate in the PACE Program, people must be eligible for Medicaid and be certified at the Medicaid nursing home level of care. The program also serves people who are eligible for both Medicaid and Medicare. Participation in the program is voluntary.

The PACE Program began enrollment and operations in Wisconsin in 1990 and is now a fully-capitated, dual Medicaid and Medicare waiver that combines Medicaid and Medicare funds into one funding stream.

As of January 1, 2002, about 430 people, aged 55 and older, were enrolled in the PACE Program at Community Care for the Elderly (CCE) in Milwaukee, Wisconsin. Some highlights of the benefits of the PACE Program include:

- **People Receive Interdisciplinary Case Management**. Each member has support from an interdisciplinary team that consists of, at a minimum, a nurse practitioner, a social worker/care manager and a RN. Other professionals, as appropriate, also participate as members of the interdisciplinary teams. The interdisciplinary team conducts a comprehensive assessment of the member's needs, abilities, preferences and values with the member and his or her representative, if any. The assessment looks at areas such as: activities of daily living, physical health, nutrition, autonomy, and self-determination, communication, and mental health and cognition. The nurse practitioner acts as the main liaison with the primary care physician.

- **People Participate in Determining the Services They Receive**. Members or their authorized representatives take an active role with the interdisciplinary team in developing their care plans. PACE staff provides support and information to assure members are making informed decisions about their needs and the services they receive.

- **People Receive PACE Services that Include** :

  - **Long-Term Care Services** that have traditionally been part of the Medicaid Waiver programs or the Medicaid Home and Community Based Waivers. These include services such as adult day care, home modifications, medications, mental health services, occupational and physical therapy, home delivered meals and supportive home care.

  - **Acute and Primary Care Services** that help people achieve their outcomes such as physician services and acute hospitalization care, and home and skilled nursing care.

  - **People Receive Help Coordinating Their Primary Health Care**. In addition to assuring that people get the health and long-term care services in the PACE benefit package, the PACE interdisciplinary teams also help members coordinate all their health care, including, if needed, helping members get to and communicate with their physicians and helping them manage their treatments and medications.

  - **People Receive Services to Help Achieve Their Employment or Recreational/Leisure Time Objectives**. Services such as daily living skills training, day treatment, and pre-vocational services are included in benefits provided by the PACE contractor. Other PACE services such as transportation and personal care also help people meet their employment goals.

  - **People Receive the Services that Best Achieve Their Outcomes**. The PACE contractor is not restricted to providing only specific services. The interdisciplinary care management team and the member may decide that other services, treatments or supports are more likely to help the member achieve his or her outcomes, and staff would then authorize those services in the member's care plan.

Appendix II: Methodology for Outcomes Assessment

Over an eleven-week period from November 2001 through February 2002, 204 PACE members were interviewed about their individual preferences related to the 14 member outcomes. Descriptive information about the scope of this assessment is provided in the table below.

Working from a randomly chosen list of 300 members, staff from CCE PACE contacted members to ask if they were willing to participate in the outcome interview. Participation was voluntary and about 20% of members contacted declined to participate, citing reasons such as- “medical problems”, “not enough time,” or “no longer in the program”.

The members chose the location of the interview; most occurred at members’ day program. Interview times were scheduled according to what was convenient for members. On average, interviews lasted 60-75 minutes. Members were allowed to end the interview at any point or to decline to answer questions, and interviewers paid close attention to members’ body language and made adjustments if the member seemed to become fatigued during the interview.

The data from the PACE interviews are representative of member experiences from people served by the PACE Program. Eventually, the Department plans to analyze the outcomes data by looking at the characteristics of the members interviewed, the presence of outcomes and individualized supports, and possibly the differences in the communities in which members live. This report does not present those analyses.

Member Assessment Interview Method and Tool

The interview method was developed by The Council on Quality and Leadership as a way to assess how quality of life for people with disabilities is affected by public services in the context of each individual's preferences about services. The tool, which can be found at the end of this appendix, was adapted for use in Wisconsin and for members of the PACE Program by the Department of Health and Family Services.

The interviewer may ask a series of questions or simply let the individual speak about issues on his or her mind, directing the conversation to cover all the areas required. One member may be asked different questions than are asked of another member. If a member is non-verbal, the interviewer will observe the member in his or her living arrangement and pose questions to the member and allow a relative or guardian who knows the member best to respond on the member's behalf. A method was devised to address health and safety concerns in case an interviewer noted a critical problem while meeting with a member. Interviewers were instructed to ensure the safety of the member by immediately discussing health and safety issues with the care manager.

Next, the interviewer meets with a representative of the interdisciplinary team, responsible for coordinating the services and supports for that PACE member. During this meeting, the representative may access case records for the individual to assist in responding to the questions. After both meetings are complete, the interviewer uses the Interview Tool to assess whether outcomes were present for the member and if supports were provided by the contractor.

Sample Selection

The sample was selected using Excel software drawing a random sample without replacement. The sample size was determined according to the number of members enrolled in each contractor by each target group, using a sample size calculator with a 95% confidence level and plus-or-minus 5% confidence interval.

Interviewer Training

Interviews were conducted by trained interviewers who achieved at least 85% inter-rater reliability in pre-interview testing. Staff from the Bureau of Developmental Disabilities Services (BDDS) and from The Management Group (TMG), a contractor with the Bureau on Aging and Long-Term Care Resources (BALTCR), were trained and tested for reliability in November 2000. These interviewers also conducted the interviews for the Family Care and Partnership Programs.

Wisconsin staff attend periodic training sessions to maintain inter-rater reliability. In addition, interviewers meet via conference call regularly during the interview process to help maintain consistency across the interview sample.

Member Outcomes Interview Tool for PACE

The purpose of this document is to add additional support to the interview process. The questions in this tool are selected from The Council on Quality and Leadership's Personal Outcomes Measures 2000 edition manual (for a listing of all of the suggested questions see the manual). These questions are to be used like the manual in picking and choosing the right questions to ask people in order to get the information needed to make decisions about the presence or absence of outcomes and supports. This list is not all-inclusive, and all questions listed will not be asked of every member. Supplemental questions were developed with input from focus groups from BDDS and BALTCR, reviewed by The Council and compiled on 11/6/00. For the Wisconsin PACE Program interviews, the DD questions were not asked.

Outcome: People choose where and with whom they live.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. How did you choose where to live? 2. What options did you have to choose from? 3. How did you decide who would live with you? 4. What do you like about your living situation? 5. What would you like to be different?	*1. Does the person have options about where/with whom to live?* *2. Does the person decide where to live?* *3. Does the person select with whom he/she lives?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. How many different residential options were shown to you? Did you visit different places before you chose where to live? 2. Did you decide to live here or did someone else? Who? 3. Did you have a choice of your roommates/ housemates? 4. Where did you live before moving here? 5. What do you like about living in your current situation? Do you dislike anything? 6. If you are not living where you want to live, is a plan in place to help you move? 7. Do your supports (family, legal guardian, caregivers, etc.) know your preference about where to live? And with whom? 8. For individuals with whom the courts have intervened, is there a rationale behind where the person is currently living versus their preference?	**(for people in substitute care facility or with family, others)** 1. How did you choose where to live? With whom you would live? 2. What do you like about your living situation? What don't you like? **(for people living in their own home)** 1. What do you like about your living situation? What don't you like? 2. What would you like to be different? 3. Where do you want to live? 4. Have you ever told anyone about wanting to move, make changes, etc? Do you know what type of setting you would like to move to? 5. Are you worried that you will not be able to remain in your own home? What worries you? 6. Do you think you have received enough help to live in your own home?	**(for people in substitute care facility or with family, others)** 1. How did you choose where to live? 2. What options did you choose from? 3. What do you like about your living situation? What don't you like? 4. What would you like to be different? 5. Do you consider your current living arrangement home? **(for people living in their own home)** 1. What do you like about your living situation? What don't you like? 2. What would you like to be different? 3. Where do you want to live? 4. Do you wish to move, make changes, etc? Do you know what type of setting you would like to move to? 5. Are you worried that you will not be able to remain in your home? What worries you? 6. Do you need more help to live in your own home?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How do you learn about the person's preferences? 2. How do you present options so the person can make informed choices? 3. Is the person living where/with whom they wish? 4. What are you doing to overcome barriers?	*1. Does the contractor know where/with whom the person wants to live or are there efforts being made to learn about the person's preference?* *2. Does the contractor support the person to explore all options so he/she can make informed choices?* 3. *Does the contractor acknowledge the person's preferences and support the person to address any barriers that prevent him/her from choosing where/with whom to live?*

Outcome: People achieve their employment objectives.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. What do you do for work/career? 2. What options did you have? 3. Who chose what you do? 4. Can you do something different if you want? 5. How did others help you with this?	*1. Does the person have the opportunity to experience different options?* *2. Does the person decide where to work/what to do?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. Can you tell me what you do during the day? 2. Do you do what you want with your days? 3. Are you retired? Do you like retirement? Are you doing things during the day that you want to do? 4. Do you have a job? If no, do you want to work? If you want to work, are there any things that get in your way? 5. Do you like your job? 6. What would be your favorite job to do? 7. Would you like more hours? 8. Do you have the educational or training opportunities you want? 9. Do you have any concerns about losing benefits if you work? Are you working to your full potential? 10. Do you have opportunities for advancement? Job transfers? 11. Do you have adequate transportation to get to work? Job interviews? 12. If you need a job coach, can you get one? 13. If you are volunteering, was it your choice or was it suggested? If it was suggested, is it a means of getting job experience?	1. What options do you have for spending time doing activities you want to do? 2. Do you work? 3. If no, would you like to work? (What do you think is keeping you from working?) 4. Do you know what you want to do? 5. Do you like the work you currently do? Is this what you want to continue to do?	1. Though work may not be an option that many people who are elderly want, we should ask that question. Some may feel that they do want a job. 2. What do you like to do during the day? Do you get to do the things you like to do? 3. "I understand you used to be a (school teacher). Are things about (teaching) that you would still like to do?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How do you learn about the person's preferences for work? 2. How do you present options to the person so they can make informed choices? 3. Is the person working where they wish? 4. How are you overcoming any barriers? 5. How do you learn about the person's job satisfaction?	*1. Does the contractor know the person's interests for work OR are efforts being made to learn about what the person would like to do?* *2. Does the contractor provide the person with access to varied job experiences/options?* *3. Has the contractor responded to the person's desires for pursuing specific work/career options with supports?* *4. Has the contractor supported the person to address any identified barriers to achieving this outcome?*

Outcome: People are satisfied with services.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. What have you gained from the services you receive? 2. What do you like about the services you receive? 3. What would you like to change? 4. Is there something more you want? 5. How do people find out if you are satisfied with services? 6. How do you let people know you are dissatisfied?	*1. What are the person's expectations/needs for services and supports?* *2. Are services and supports provided to meet the person's expectations and needs?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. Are people helpful? 2. Are you comfortable as a participant in PACE? 3. Is PACE worthwhile? 4. Behavior changes indicate satisfaction - If someone is speaking for the person be sure to ask why they think someone is satisfied or not. 5. Who checks to make sure that you are pleased with what is going on? 6. Are things in your life better since you enrolled? How? If no, why? 7. If you had a complaint, did the CONTRACTOR help you resolve it? 8. Would you recommend your providers to others? 9. Would you recommend PACE to others?	1. What do you like about the services you receive? 2. What don't you like about the services you receive? 3. Are new needs addressed to your satisfaction? When new needs arise, are they met? 4. Did you have to wait for services? If you had to wait, were you comfortable with the length of time and what happened? 5. Did the people accommodate your schedule for meetings? For communication? For care planning? For determining eligibility? 6. Are hours of service flexible to accommodate your schedule?	1. What do you like about the help you receive? What don't you like? 2. What would you like to change about the services you receive? 3. If you are unhappy or disagree with a service, do you know whom you can talk to? 4. Do people do what you want them to? 5. If people come into your home to provide services, is your home and personal belongings respected and kept the way you want? 6. Who do you talk to about the kind of help you need or want? 7. Does you care manager/caregiver/service provider communicate with you in a way you understand? 8. Do you think your care manager/caregiver/ service provider is aware of your needs relating to the type of disability or illness you have?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. What methods have been developed to determine the person's satisfaction with services? 2. What is done to increase satisfaction if the person has concerns? 3. How have you determined the person's expectations for services and supports? 4. Are there any barriers that affect the outcome for the person?	*1. Does the contractor actively solicit the person's opinions about services and supports?* *2. Does the contractor respond to the person's feedback regarding supports and services?* *3. Are there changes/accommodations made to increase the person's satisfaction?*

Outcome: People choose their daily routine.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. What is your day usually like? 2. What do you do and when? 3. Can you make a change in times you do things to suit your needs? 4. Who decides when you eat meals? 5. Who decides when and how often you bathe?	*1. Does the person have choice about what to do during the day?* *2. Does the person choose when, where, and for how long he/she will engage in routine activities?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. Do you have a daily routine? 2. Do you have established ways of doing things? 3. How involved are you in household tasks? 4. Are you able to "sleep in?" 5. If you want to do something special on short notice, can you do so? 6. Is there a required chore list where you live? If you do not participate, what happens? 7. Do you plan your day? How do you do that and who, if anyone, helps you? 8. Is there flexibility in your day according to your preferences?	1. Tell me about your day. 2. Are you able to go to bed when you want? 3. Are you able to wake up/get up when you want? 4. Are services in place to accommodate your schedule? 5. Are you able to continue your usual activities and hobbies with services in place? 6. Are your services and supports in place that allow you to continue your usual activities and hobbies? 7. What happens if you don't want to eat when the others in the house do? 8. Do you have certain hours or days when you are scheduled to have laundry done, take baths, clean your room, etc?	1. Are you able to get up in the morning and go to bed at night when you want? 2. Are you able to eat what you want, when you want? 3. Are you able to bathe when you want? 4. Are you able to wear what you want? 5. Does the help you get support activities that are important to you? 6. Do the help and supports you have in place now support you to continue your usual activities and hobbies (continue to read books, take walks, etc)? 7. Are there rules that you feel you must follow?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How do you know what the person likes to do and when he/she prefers to do it? 2. How do you learn about the person's preferences for routines and leisure time? 3. How are options explored and experiences provided? 4. How do you honor the personal preferences of the person" 5. Are there any barriers that affect the outcome for the person? How is the person supported to achieve this outcome?	*1. Does the contractor know the person's preferences for daily routine?* *2. Does the contractor make accommodations to honor the person's preferences?*

Outcome: People have privacy.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. Are there times when you want to be alone? 2. Where can you go to be alone? 3. Where do you visit with your friends/family in privacy? 4. How do you have privacy when you make personal phone calls? 5. Are there times when you don't have the privacy you want? 6. If you need help with personal hygiene, how do you decide who will help you?	*1. Does the person have time during the day for private activities and general privacy?* *2. Can the person go somewhere to be alone or with friends?* *3. Is privacy provided when the person desired/requests privacy?* *4. Is the person satisfied with the level of privacy?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. Do you have your own room? 2. Do you have access to your own room? 3. Do you share a room with someone? Do you choose to share with this person? 4. Do people knock on the door before entering? Can you close your door tightly? 5. Is there a lock on the door? 6. Can you keep your belongings locked up? 7. Can you have private time with whom you want in your bedroom? Are you allowed visitors of the opposite sex in your room? 8. Are family members and friends welcome in your room? 9. Are there house rules that infringe on your privacy? 10. Phone time - can you have private time? Can you have your own phone? 11. Is your personal care done in private? Do you have a choice of who does your personal care? 12. Do you open your own mail? 13. Do you hear people talking about you when they should not? 14. When others assist you by talking to your doctor, is the conversation done in private?	1. Where can you go when you want to be alone? 2. Do you have privacy to visit with or talk on the phone with family and friends? 3. Are there times you don't have the privacy you want? 4. Are there times you are uneasy about sharing information with your caregivers? 5. When you get help taking a bath, getting dressed…is it done as privately as you would like? 6. Are you comfortable with the people who help you? 7. Are services and equipment provided unobtrusively, or in a way that does not draw unwanted attention to your condition?	**(for people in substitute care facility or with family, others)** 1. Do you have a place to go when you want to be alone? 2. Do you have privacy to visit with or talk on the phone with family and friends? 3. Is you mail delivered on time and unopened? **(for all older persons)** 1. Are there times when you do not have the privacy you want? 2. If you receive help taking a bath, getting dressed…is it done as privately as you would like? 3. Are you comfortable with the people who help you complete private tasks? 4. Are there times when you can refuse to share information with your caregiver or other "service providers?" 5. Do your "service providers" call ahead or schedule visits? Do they identify themselves when they visit? 6. Do your "service providers" knock and receive permission before entering your home or living area? Do they respect your right not to want them to come in? (same questions with apartment management) 7. Are your private living areas or belongings left alone? 8. Are services and equipment provided unobtrusively or in a way that does not draw unwanted attentions to your condition?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How do you learn about the person's desires/needs for privacy? 2. How do you accommodate his/her desires and needs. 3. How are methods to address opportunities for the person's privacy individualized for the person? 4. Are there any barriers that affect this outcome for the person? How is the person supported to address barriers?	*1. Does the contractor know the person's preferences for privacy or are efforts being made to learn about preferences?* *2. Does the contractor make accommodations to honor the person's preferences?*

Outcome: People participate in the life of the community.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. What kinds of things do you do in the community(shopping, banking, synagogue, church, school, hair care) 2. What kinds of recreational or fun things do you do in the community (movies, sports, restaurants, events) 3. How do you know what there is to do? 4. Who decides where and with whom you go? 5. Is there anything you would like to do in the community that you don't do now? What would you need to make this happen? 6. What supports do you need to participate as often as you'd like in community activities?	*1. What does the person do when he/she participates in the life of the community?* *2. How often does the person participate in the life of the community?* *3. Is this type and frequency of participation satisfactory to the person?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. How often do you go to the grocery store? Do you shop for your own groceries? 2. Do you go into the community to do things? Is it often enough for you? 3. If a special event comes up, can you go to it? 4. Do you have transportation? 5. Do you choose your events? 6. How do you know what is going on? If you need help with learning about upcoming events, who helps you? 7. Are there "typical" events in the community you are able to attend? (church, shopping centers)	1. Do you get out of the house as much as you wish? 2. What things do you like to do in the community? 3. What do you do when you get into the community?	1. What kinds of things do you do when you get out of the house (shopping, banking, church, synagogue, school, hair care)? How often? 2. How do you find out about activities or events going on in your community/area/ neighborhood? 3. Do you decide where and with whom you go out in the community? Do you get out in the community often enough? 4. Is there anything you would like to do with other people that you don't do right now? 5. Is there anything that would make going out of the house more comfortable for you or for people around you? 6. How do you get around? 7. Do you get out in your neighborhood as much as you want to?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How is the person informed of options available in the community? 2. How do you learn about what the person prefers to do ? 3. How do you learn about how often the person likes to be involved in community activities? 4. What supports does the person need to participate in community activities? How are those provided? 5. Are there any barriers That affect this outcome for the person? How do you assist the person in overcoming these barriers?	*1. Does the contractor know what the person would like to do in the community OR are efforts being made to learn about the person's preferences?* *2. Does the contractor know how often the person would like to engage in community activities OR are efforts being made to learn about the person's preferences?* *3. Does the contractor provide the person access to information about options for community participation?* *4. Does the contractor provide support to the person to do the things s/he wants to do?*

Outcome: People have personal dignity and respect.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. How does staff treat you? 2. What do you think about things you do at home, school, work? Are they interesting? 3. Do people listen to your comments and concerns? 4. Do you think people treat you as important?	*1. How do others treat the person?* *2. Does this treatment demonstrate respect for the person?* *3. Do interactions with others reflect concern for the person' opinions, feelings, and preferences?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. Are you called by the name you prefer to be called? 2. Do others listen to your opinions? Do others ever outvote your decision? 3. Are you able to communicate in another language? Are translators made available? 4. If you have an augmentative communication device, are you permitted to use it? Does it work? 5. Are your cultural beliefs acknowledged? 6. Are you able to use your own strengths? Do you feel rushed by caregivers and not given a chance to perform tasks independently? Are you able to demonstrate mastered skills? 7. Do others talk to you versus your caregiver when you are present? 8. Are you treated as an adult, in an age appropriate manner? 9. Do others knock on the door before entering your room? 10. Does your service plan maximize your potential?	1. Do others talk to you directly or do they talk to others when you are present?	1. Do people call you by your preferred name? 2. Do you feel your opinions are valued and respected? Do your care manager and service providers listen to you? 3. Do you feel people listen to your comments and concerns? 4. Do people try to provide the kind of care you would like to receive?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How do you know if the person feels respected? 2. How is respect considered in decisions regarding supports, services, and activities? 3. Are there any barriers that affect the outcome for the person? 4. How do you assist the person to overcome barriers to this outcome?	*1. Does the contractor know what is important to the person with regard to respect?* *2. Does the contractor take action to ensure that interactions with the person are respectful?* *3. Have supports need to enhance the person's self-image been identified and implemented?*

Outcome: People choose their services.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. What services are you receiving? 2. When, where and from whom do you receive the services? 3. Who decided what services you would receive? If not you, who & why? 4. Are these services the one's you want? 5. Do you have enough services? 6. Can you change services/providers if you want?	*1. Does the person select the services and/or supports that he/she receives?* *2. Do the services/supports focus on the person's goals?* *3. Does the person have choices about service providers?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly)**
1. Do you choose the services you get? More than one option? 2. Is there a way to increase your choice making ability? Do you have the support to help you in making decisions? 3. If speaking for the person: How do you know when he/she has a preference? 4. Can you ask for a different provider? Will your choice be honored? 5. Can you choose not to have a service? 6. Who recommended your doctor? 7. Do you still have the same doctor as when you entered PACE? If not, why? 8. Do you still have the same therapist as when you entered PACE? If not, why? 9. Do you still have the same personal care worker as when you entered PACE? If not, why? 10. Who chooses your (barber, hair stylist, bank, grocery store, etc.)?	1. Do you receive support in order for you to choose your services? 2. If you are uncomfortable with your case manager, can you choose a new one if you wish? 3. Can you choose your providers? 4. Were you provided with options for services? 5. Were you provided with options for providers? 6. Did you get sufficient/enough/adequate help getting your services? 7. Did you have to wait to receive services? How long? Why did you have to wait? 8. Were you given options to the extent of assistance you needed to choose your services? 9. Are you able to assist with the hiring of your personal care worker? 10. Are you able to be as independent as you wish to be when choosing your services? (Do others take too much control away from you?) 11. Who chooses where you shop for groceries, who does your hair, where you bank, etc?	1. What help are you receiving? 2. When, where and from who do you receive this help? 3. How did you decide what help you would receive? 4. How was your care manager, caregivers, service providers chosen? 5. Were you given a choice in the help that is provided? Were you given more than one option? 6. Did you have enough time to make decisions? 7. Do you feel your opinions were listened to? 8. Do you have enough help to continue with your usual activities? 9. Do you know who to call if you want/need some help? If you want to change something about the help you are receiving? 10. Where do you bank, get your hair done, get spiritual support, etc?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How do you determine the services desired by this person? 2. How were options for services and providers presented to the person? 3. How were the person's preferences considered when presenting options? 4. If the person has limited ability/experience to make decisions, what do you do? 5. How do you assist the person to overcome barriers to this outcome?	*1. Does the contractor actively solicit the person's preferences for services and providers?* *2. Does the contractor provide options to the person about services and providers?* *3. Does the contractor honor the person's choices about services and providers?*

Outcome: People remain connected to informal support networks.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. Who are the people in your life that you count on? 2. Who do you want to talk to or be with when you go through rough times? 3. Have you lost contact with family members or others? 4. Is the contact enough? If no, why? 5. What type of frequency of contact would you prefer?	*1. Does the person have a natural support network?* *2. If the answer to #1 is yes, what contact does the person have with people in the network?* *3. Is this contact satisfactory to the person?* *4. If the person does not have a natural support network, is this due to personal choice or due to natural circumstances?* *5. If due to personal choice or natural circumstances, the outcome is present.*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. Do you see your family members as much as you want? 2. Do you talk with family members or communicate with them by writing as much as you want? 3. How do you stay in touch with your family members and others who are most important in your life? 4. Are you able to attend family events? If no, why? 5. Do you go to family events? Weddings? Funerals? Anniversaries?	1. Have you been provided the supports to maintain contact with family and friends? 2. Do you have enough contact with your family and special people in your life?	1. Do you have contact with your family members? If not, what is the reason? Is this contact enough? 2. Do you go to family member's homes and vice versa? 3. Do you participate in family activities and events that are meaningful to you? 4. If not, why? What are the problems (transportation, need support, etc)? 5. Are there family members you feel you can count on?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How do you learn about the person's support network? 2. What do you do to support contact? 3. If there is no contact, what is done to assist the person to re-establish contact if desired? 4. If contact is with parents only, what do you do to expand/extend the network 5. What do you do if the extent and frequency of contact is unsatisfactory to the person? 6. Are there barriers preventing the person from remaining connected with people s/he identifies as a part of this support network? How do you assist the person to overcome these barriers?	*1. Has the person's natural support network been identified by the contractor?* *2. Does the contractor know the status of relationships within the person's support network?* *3. Does the contractor provide support for the person's relationships within the network if needed and requested?*

Outcome: People are safe.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. What kinds of safety risks are you concerned about? In the home/community? 2. Do you feel safe at home? 3. Is there anyplace you don't feel safe? 4. What would you do if there were an emergency? 5. Do you have safety equipment? 6. Is your living environment clean and safe of health risks?	*1. Does the person live, work, and pursue leisure activities in environments that are safe?* *2. Does the person know how to respond in the event of an emergency situation?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. Do you feel safe in your home? 2. Are there reasonable precautions/equipment to reduce the risk of break in? 3. Have you been taught safety strategies? 4. Are there adaptation or modifications in your home to reduce the risks of accidents? 5. What response systems are available should an accident occur? Who would help you? Would anyone know if an unfortunate even occurred? 6. Has a risk/safety assessment been done? 7. Are there neighbors who watch out for you? 8. What would you do if…..? (scenarios) 9. Who takes care of snow shoveling?	1. Do you ever feel unsafe in your home, in the community, or other setting? 2. If you were in a vulnerable situation, what would you do? (what would you do if… scenario) 3. Are you aware of the consequences of your decision to take a risk? 4. Do you need any additional adaptive equipment in order to help you feel safer? 5. Are there any options or resources that could make staying in your own home easier and safer? 6. Do you feel there are any potential risks to remaining in your home?	1. Do you feel safe at home? Have friends or family raised concern about your safety? 2. How safe do you feel when you enter or exit your home? Move from one room to another? Manage stairs? 3. Have you ever been left alone for so long that you felt unsafe? 4. Is there anywhere in the home that you do not feel safe? 5. Have you had any accidents (falls, burns)? Do you worry about falls or accidents? 6. If you fall, can you get up by yourself? 7. What would you do if there were an emergency (fire, illness, injury, or severe weather)? 8. How do you call for help? Do you know who to call for help? Do you have services or someone to help you if there is an emergency? 9. Do you have safety equipment in your home (smoke alarm, weather alert, fire extinguisher, a way to see who is at the door before it is opened)? 10. Do you feel safe in your neighborhood? 11. Are there any "ADL's" (dressing, bathing, eating) that you have difficulty with by yourself? How do you do them? Do you feel there are any safety issues with completing these tasks? Are you afraid that you might hurt yourself? 12. If you had an injury or spell of illness that made being at home unsafe, do you have a plan to ensure your safety? That you will be able to remain in your home? Do you have anyone who could help you? How would you cope?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How do you know that the person is safe? 2. How do you learn about safety issues that are of concern to the person? 3. What do you do to ensure that places where the person spends time are safe? 4. Are there any barriers to the person's safety? 5. How do you assist the person to overcome barriers to this outcome?	*1. Has the contractor identified safety issues for the person?* *2. Is the person provided with supports to address identified safety concerns if needed and requested?*

Outcome: People are treated fairly.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. Have there been times when you thought you were treated unfairly or your rights were violated? 2. With whom can you talk when you have concerns about your rights? 3. Are any of your rights formally limited? If yes, did you agree to? 4. What is being done to change the situation? What assistance are you getting so you can exercise this right in the future?	*1. What rights limitation or fair treatment issues have been identifies by this person?* *2. If none, the outcome is present.* *3. If there are limitations or fair treatment issues, was due process provided?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. How informed are you about the right to file complaints/grievances? How often? 2. Do people listen when you voice a concern? 3. Is there anything you've asked for and been denied? If so, why? 4. Are you being billed for services you aren't using? 5. Do you feel you are treated fairly? Have you been treated fairly? 6. Have you ever complained or filed a complaint? Were you treated differently after you filed a complaint? In what way? Do you feel free to complain again without negative impact? 7. If you had a complaint, was anyone available to help you file one? 8. Are you paying for services that should be provided by the CONTRACTOR?	1. Is there anything you have been denied? If so, why? 2. Are you being billed for services you are not using? 3. Have you ever complained or filed a complaint? Were you treated differently after you filed a complaint? In what way? Do you feel free to complain again without negative impact? 4. If you had a complaint, was anyone available to help you file one? 5. Are there any restricting rules in your life that you don't agree with?	1. Is there someone you can talk to if you have concerns about how you are being treated?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. Does the person have rights limitations? What is the reason for limitations? 2. How was it decided limitation was necessary? Who consented to limitations? 3. Who reviewed the limitation? What is the plan to remove the limitation? 4. How ling will the limitation be in place? 5. What are the barriers that affect the outcome for the person? 6. How do you assist the person to overcome barriers to this outcome?	*1. Has the contractor solicited info about rights violations or fair treatment issues from the person?* *2. Have procedures for addressing the person's concerns been implemented?* *3. Are the procedures used by the contractor consistent with due process principles?*

Outcome: People have the best possible health.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. Do you feel healthy? If no, what bothers you? 2. What do you do to stay healthy? 3. What health concerns do you have? 4. Are you seeing a doctor, dentist, and health care professionals? 5. Do you take medications? If so, what is it, and how does it help? 6. If you think medications, treatments, or interventions are not working, what is being done?	*1. Does the person see health care professionals?* *2. Have health care professionals identified the person's current best possible health situation, addressing any health care issues or concerns, and interventions?* *3. Have health intervention services been selected by the person in consultation with the health care professional?* *4. Have health intervention services as desired by the person been effective?* *5. If due to personal choice, the outcome is present.*

Supplemental guidance questions for members by Target Group:

Key question for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly:**
1. Who is your primary physician? 2. If you have a health problem, whom do you tell about it? 3. Who helps you make health care decisions? 4. Over the past year, has your health condition gotten better? Remained the same? Gotten worse? Why do you feel that way?	1. How is your health? Do you have any health problems? 2. Do you have any health problems that interfere with activities you like to do or would like to do? 3. Have you ever had pressure ulcers/sores? 4. Do you have any problems getting to the bathroom or having accidents? 5. Are you able to sleep? Do you rest during the daytime? 6. Are you physically comfortable and free from pain? 7. Do you ever feel lonely? Anxious? Sad? Like life is not worth living? 8. Do you rely on alcohol or drugs? 9. Have you discussed any health or substance use issues with your doctor or someone else? 10. Do you have preventive health screenings?	1. How is your health? Do you have any health problems? How often have you been hospitalized in the past six months? Gone to the ER or emergency clinic? 2. Do you have any health problems that interfere with activities you like to do or would like to do? 3. How do you get to the doctor? Dentist? Therapist? Does someone go with you do your medical appointments? 4. Are you able to see your doctor when you need to? Do you see anyone else regarding your health (public health nurse, therapist, etc)? 5. Who do you talk to if you have a question or concern about your health or medications? 6. How do you get your medications? Do you ever forget to take your medication? Does someone help you take or remember your medications? 7. Can you tell me what medications you are taking and why? Are you taking different medications from different doctors? Does one doctor know all the medications you are taking? Do you ever take anyone else's medications? 8. Are you physically comfortable and free from pain? 9. Have you discussed feelings of sadness, depression, anxiety, etc. with your doctor or other person? 10. Do you exercise? 11. Do you get preventative care (mammograms, prostate screening, etc)? 12. What kinds of things do you eat on most days? 13. Have there been times when you have gone without food, water, or medicine?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How have you explored health issues with the person? 2. What supports does the person need to achieve or maintain best possible health? 3. Who provides the support? 4. How was this decided? 5. How do you assist the person to overcome barriers to this outcome? 6. What organizational practices, values, and activities support this outcome for the person?	*1. Does the contractor know the person's definition of best possible health?* *2. Are supports provided for the person to promote and maintain best possible health if needed and requested?* *3. Does the contractor respond to the person's changing health needs and preferences?* *4. Based on the answers to these questions, are there individualized supports in place that facilitate this outcome?*

Outcome: People are free from abuse and neglect.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. Do you have any complaints about how you are being treated by anyone? 2. Have you been hurt by anyone? 3. Has anyone taken advantage of you? 4. Does anyone yell or curse at you? 5. Who would you tell if someone hurt you or did something you did not like? 6. Do you know what abuse is? 7. Have you been abused?	*1. Have there been any allegations of abuse or neglect by or on behalf of the person?* *2. Is there any evidence that the person has been abused, neglected, or exploited?* *3. Is the person experiencing personal distress from a previous occurrence of abuse?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the member (input from BALTCR - elderly):**
1. Have you reported any incidents of abuse or neglect? If yes, were you protected from the abuser? Was there an investigation? Was there any follow up? 2. Would you feel comfortable reporting any incidents of abuse or neglect? 3. Who would you call if you were abused or neglected? Do you know the telephone number? 4. Have you ever been afraid while in the care of a paid caretaker? 5. Have you ever been held against your will? 6. Are you free to exit your room at any time? Your residence? 7. Do you live in a clean environment? 8. Are you free from verbal abuse? 9. Have you been abused in the past? If so, how long ago? 10. Do you feel you are treated badly? (Does the treatment need to be reported?)	1. Have you ever been left alone for long periods of time? 2. Has anyone ever kept you from having food or water? 3. Does anyone yell or curse at you, making you afraid or uncomfortable? 4. Have you ever been subject to unwanted sexual advances? Have you ever been forced to perform sexual acts you did not want to do? 5. Have you ever told anyone? Do you know who to talk to? Do you have someone you feel comfortable with that you can talk to? 6. Do you know what abuse is? *(outcome)* Has anyone explained what abuse is? *(support)* 7. Do you know what neglect is? Has anyone explained what neglect is? 8. What does your spouse/partner/child/ caregiver do when they get angry? 9. Does your spouse/partner/child/caregiver ever act in a way that frightens you? 10. Are you afraid of your spouse/partner/child/ caregiver? 11. Have you ever been punched, kicked, hit or hurt in a way by a member of your family or caregiver? Were you threatened or forced to do things you did not want to do? 12. Does anyone depend on you for money or other help (through feelings of guilt or sympathy)? 13. Has anyone who takes care of you ever pressured you for money other things of value?	1. How are things going in your relationship with your spouse/partner/child/caregivers at home? 2. What does your spouse/partner/child/ caregiver do when they get angry? Does this hurt you in any way? 3. Does your spouse/partner/child/caregiver ever act in a way that frightens you? 4. Are you afraid of your spouse/partner/child/ caregiver? 5. Have you ever been punched, kicked, hit or hurt in a way by a member of your family or caregiver? Were you threatened or forced to do things you did not want to do? 6. Have you ever been forced to do sexual acts you did not wish to do? 7. Have you ever told anyone? Do you know who to talk to? Do you have someone you feel comfortable with that you can talk to? 8. Have you ever been left alone for so long you have felt unsafe? Anxious? Worried? 9. Are there times when you do not have access to money? 10. Have people ever kept you from having food or medicine? 11. Does anyone depend on you for money or other help (through feelings of guilt or sympathy)? 12. Has anyone who takes care of you every pressured you for money or other things of value?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. Does the person understand abuse and neglect? If yes, how do you know that? 2. What has been done to inform the person? 3. What activities/practices are in place for the person to prevent abuse and neglect? 4. How do you assist the person to overcome barriers to this outcome?] 5. What organizational practices, values, and activities support this outcome for the person?	*1. Does the contractor know about the person's concerns regarding abuse and/or neglect?* *2. Does the contractor provide the person with information and education about abuse and neglect?* *3. Does the contractor provide support for the person if there have been concerns expressed or occurrences of abuse and neglect?*

Outcome: People experience continuity and security.

Selected questions from The Council's Personal Outcomes 2000 Manual to assess outcomes:	Decision making questions:
1. How long has your support staff worked with you? 2. Is there anything you want to change? 3. What is your source of income? 4. Do you have enough money to pay your expenses? Are there things you have to do without? Is your financial sit. acceptable? 5. Renter's Insurance? Home Owners Insurance? Life insurance?	*1. What changes have occurred for the person over the past one to two years?* *2. Are changes determined by the person?* *3. Is the control over changes similar to that exercised by other people?* *4. Does the person have economic resources to meet his/her basic needs?*

Supplemental guidance questions for members by Target Group:

Key questions for the CONTRACTOR member (input from BDDS - DD):	**Key questions for the CONTRACTOR member (input from BALTCR - PD):**	**Key questions for the CONTRACTOR member (input from BALTCR - elderly):**
1. Are you able to sustain the life you want? 2. Do you have the same staff most of the time? 3. Are there people in your life whom you feel you can trust? 4. How many times have you moved? 5. If you complain, are you afraid you will have to move? 6. How long have you lived here? How much longer do you think you will live here? 7. Do you have enough resources/money to feel secure and get the things you need? 8. How do you deal with changes? How do others handle changes in your life? 9. Do you control most of the changes in your life?	1. Do you control the changes that occur in your life? 2. Has anyone talked to you about planning for the future? Financial planning? 3. Has anyone ever talked to you about the kind of care you would like to receive? 4. Has anyone ever talked to you about the kind of care you would like to receive at the end of your life?	1. Do you know the name of your care manager and how to contact him or her? 2. Do other people help you? Do you know how to get in touch with them? 3. Does the same person come to your house? How many caregivers have you had over the past year? Month? 4. Do you like your caregivers? Do you think your caregivers are familiar with you and your preferences? 5. Do your helpers come on time? Do they come when they are scheduled? 6. Do you feel you can change the times, dates that your helpers come? 7. Do you have family, friends, or neighbors that you can count on to provide some help or check on you from time to time? 8. Do your helpers know about the things you have done in your life and the memories or mementos that are important to you? 9. Do you have enough money to pay for expenses (food, rent, clothing, health care, insurance, transportation) and leisure activities (getting hair done, going out to lunch)? 10. Do you have insurance to protect your valuables, provide you the burial you desire? 11. Do you feel you have some control over the changes that occur in your life?

Selected questions from The Council's Personal Outcomes 2000 Manual to assess supports:	Decision making questions:
1. How are changes handled and planned for? 2. How is the importance of staff continuity defined for the person and addressed through the support process? 3. How is the sufficiency of the person's economic resources determined? 4. What supports are provided if they are insufficient? 5. How is the person assisted to obtain additional resources? 6. How does the contractor ensure that the person has protection for his/her personal resources? 7. How do you assist the person to overcome barriers to this outcome?	*1. Does the contractor know what is required for the person to experience continuity and security or are efforts being made to learn about the person's preferences?* *2. Are supports provided to assist the person in attaining and maintaining continuity and security?*

Appendix III: CCE PACE Member Outcomes

The table below shows the summary results of the 204 members interviewed during the winter of 2002. This specific data will be used for quality improvement efforts and as an initial benchmark for subsequent outcome assessments.

Number of Outcomes Met/Supports Provided

	Frail Elderly	
	Outcomes	*Supports*
Choose Where to Live	89	73
Participate in Community	84	47
Connected to Informal Networks	117	101
Safe	143	85
Best Health Possible	75	113
Free from Abuse and Neglect	176	48
Continuity and Security	98	37
Employment Choices	91	53
Satisfied with Services	129	121
Choose Routines	99	57
Privacy	161	63
Respect	147	64
Choose Services	39	20
Fair Treatment	105	55
# Interviews	**204**	**204**

Percent of Outcomes Met/Supports Provided

	Frail Elderly	
	Outcomes	*Supports*
Choose Where to Live	43.6%	35.8%
Participate in Community	41.2%	23.0%
Connected to Informal Networks	57.4%	49.5%
Safe	70.1%	41.7%
Best Health Possible	36.8%	55.4%
Free from Abuse and Neglect	86.3%	23.5%
Continuity and Security	48.0%	18.1%
Employment Choices	44.6%	26.0%
Satisfied with Services	63.2%	59.3%
Choose Routines	48.5%	27.9%
Privacy	78.9%	30.9%
Respect	72.1%	31.4%
Choose Services	19.1%	9.8%
Fair Treatment	51.5%	27.0%